UNIVERSITY OF ALBERTA

NURSES' PERCEPTIONS OF PRACTICING FAMILY-CENTRED CARE IN THE NEONATAL INTENSIVE CARE UNIT

By

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Abstract

Family-centred care has become the underpinning approach promoted by families, nurses and health care professionals in paediatric practice. Although this method of health care delivery underscores the importance of family functioning and family development, incorporation of this mode of care into the Neonatal Intensive Care Unit (NICU), has resulted in many challenges. Nurses are in a unique position to help facilitate a positive family-centered care experience for families during their hospitalization. Using an interpretive phenomenological design, this study explores nurses' experiences of family-centred care practice. Data were collected through small group interviews with five staff nurses. Analysis of the participants' narratives reflected positive and negative practice encounters. Amongst the findings of this research are implications for nursing in the areas of education provision, positive workplace culture and unit policy development. Recommendations include family-centred care education, communication tools, promoting a respectful team building environment, primary care practice directives and peer mentoring.

[*Keywords: family-centred care, neonatal intensive care unit (NICU), nursing, practice, phenomenology*]

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Dedication

This dedication goes to all those who supported me throughout the process of completing this thesis, with a special thank you to my family: Graeme and Jacob, my two children; my husband Stephen; my parents, Rilla and Allan Bevan; and my sister Alana.

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CHAPTER 1: INTRODUCTION

Over the last two decades, family-centred care has become the underpinning approach promoted by families, nurses and other health care professionals in paediatric and neonatal care units today. It evolved from a philosophy where the family is the primary resource for promoting a child's healthy development. With the growing body of knowledge exploring family-centred care, there has been a dramatic shift from the traditional paternalistic model of health care delivery to one incorporating the family as the centre of care. The family-centred care vision advocates the presence and involvement of families in the care of their children through respectful and supportive interactions with health care team members (American Academy of Pediatrics Committee on Hospital Care, 2003). The goal of practice is to improve the self-determination and self-efficacy of both the patient and their family. Having an infant admitted to the Neonatal Intensive Care Unit (NICU) is an emotional and difficult experience for family members. Implementing a family-centred approach in this environment has been suggested to alleviate some of the stresses these families experience during their NICU stay (American Academy of Pediatrics Committee on Hospital Care; Harrison, 1993).

Background

In 1987, in an attempt to address both the psychological and physical needs of families and hospitalized children, the Association for the Care of Children's Health (ACCH) proposed a progressive vision of health care delivery, acknowledging the importance of the incorporation of families into components

of health care delivery to children (Shelton, Jeppson & Johnson, 1987). This practice model, entitled family-centred care, contrasted with previous practices where health care delivery was dictated by the health care provider within an impersonal institution (Shelton et al.). The concerns experienced by patients and their families were too often ignored; care involving the paediatric population was not family-focused (Cohen, 1999).

In 1992, the ACCH was replaced by the development of the Institute For Family-Centered Care in an effort to establish a North American family-centred care framework. Over the past few decades, the family-centred care movement has steadily progressed in its implementation into the health care system, with the process still continuing to evolve and expand (Bruce & Ritchie, 1997).

The family-centred care philosophy involves the intrinsic participation of patients and families in their own health care decisions (Ahmann, 1994; American Academy of Pediatrics Committee on Hospital Care, 2003; Harrison, 1993; Shelton et al., 1987). This ideology engages the collaboration of the patient, their family and the health care professional in supporting and facilitating improved access to information required in making health care decisions, while still respecting and supporting the diverse needs of the patient and their family (Harrison; Shelton et al.). This framework dictates how care should be delivered in hospitals, communities and clinical settings today and has shaped how policies, programs and even facility designs have developed (American Academy of Pediatrics Committee on Hospital Care; Johnson, Jeppson & Redburn, 1992).

Family Centred-care Core Principles

The principle elements of family-centred care are components in providing children and families the best available care. A common theme in the delivery of this philosophy is caring collaboration. At the core of this practice are a number of key principles described by the Institute For Family-Centered Care and outlined in *Caring for Children and Families: Guidelines for Hospitals* by Johnson et al., 1992, p. 6.

- Recognizing that the family is the constant in a child's life, while the service systems and personnel within those systems fluctuate.
- Facilitating family professional collaboration at all levels of health care: care of an individual child; program development, implementation and evaluation; and policy formation.
- Honouring the racial, ethnic, cultural and socioeconomic diversity of families.
- Recognizing the family strengths and individuality and respecting different methods of coping.
- Sharing with parents, on a continuing basis and in a supportive manner, complete and unbiased information.
- Encouraging and facilitating family-to-family support and networking.
- Understanding and incorporating the developmental needs of infants, children and adolescents and their families into health care systems.
- Implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families.
- Designing accessible health care systems that are flexible, culturally competent and responsive to family identified needs.

The described elements of family-centred care are components in providing children and families the best available care. A common theme in the delivery of this philosophy is caring collaboration.

Defining Family-Centred Care

Although the family-centred care philosophy has been clearly defined by the Institute For Family-Centered Care, this concept has been historically difficult

to conceptualize and implement in both the neonatal and paediatric settings (Johnson et al., 1992; Rushton, 1990). Rushton states that "parents and professionals have been struggling to reach consensus regarding the definition of the term as well as the design of a family-centred approach to care" (p.68). Furthermore, health care professionals remain uncertain as to what family-centred care really means in their area of practice (Bradshaw, Coleman & Smith, 2003; Ahmann, 1994; Rosenbaum, King, Law, King & Evans, 1998). While many health providers will agree that incorporating families into the care of their children is paramount in the context of quality care, many professionals define the family-centred care ideology differently and often struggle with their own commitment to this philosophy (Bradshaw et al.; Rushton). Devising strategies for the facilitation of the family-centred care tenets remains a concern among health care professionals, institutions and families today especially in acute care settings where multiple barriers for its implementation can be overwhelming (Bruce & Ritchie, 1997; Harrison, 1993; Johnson et al., 1992). These challenges are still present, reflecting a discrepancy between the philosophy and the reality of practice.

Research Questions

My research question is two-fold: What are nurses' perceptions and reported practices in implementing family-centred care in the NICU setting? What advice might nurses provide for facilitating a more consistent family-centred care approach into practice?

Purpose of the Study

The purpose of this study was to explore nurses' experiences of practicing family-centred care in the NICU environment. The nurses' perception of family-centred care and whether or not their own practice reflected this approach were studied. The aim of this study was to determine how the well-being of the neonate, their families and the neonatal nursing staff might be enhanced. Identifying the nurses' perception of both enabling and challenging experiences assisted in uncovering the realities of practice. An improved understanding of nurses' ability to practice with family-centred care principles is essential in providing direction to enhance effective family-centred approaches to health care delivery. This knowledge and understanding has significance for those involved in providing neonatal care.

Definition of Terms

Neonate

A neonate is a newborn infant who is less than 44 weeks adjusted (corrected) age. Adjusted age includes preterm infants born before 37 weeks gestation and who have a corrected gestational age of less than 44 weeks post conception age, as well as term infants less than 28 days of age.

Family

Bruce (1993) describes the family as "parents, guardians, grandparents, and siblings, and any other family relative or friend who is significantly involved with the child's everyday life or care" (as cited in Letourneau, 1994, p.86).

Nurses

A staff nurse provides nursing care to both neonates and families in the NICU setting. The direct neonatal care ranges from less intensive, Level II care to advanced, Level III care. Infants, who require Level III nursing, are babies needing complex, invasive monitoring and interventions such as ventilation and inotropic support, total parenteral nutrition and intense hourly monitoring. Level II describes infants who still require an intensive care environment but need less interventional support from equipment and pharmacologic agents. Level III nurses typically provide care for one to two infants whereas Level II nurses are characteristically responsible for three infants on a given shift.

Perception

Perception is the nurse's interpretation of any given aspect of family-centred care, as described by that nurse.

Primary care nursing

"Primary care nursing is an organizational system of care which emphasizes the deliver of comprehensive, individualized and continuous nursing care" to a select patient population (Sellick, Russell & Beckmann, 2003, 545).

CHAPTER II: REVIEW OF THE LITERATURE

The philosophy and principles of implementing family-centred care into practice have been explored extensively in the literature. The purpose of this literature review is to summarize the research related to the realities of facilitating the family-centred care concept in the NICU setting. Briefly, the benefits associated with this delivery model in the NICU are outlined. Barriers, related to implementing family-centred care standards, are identified with respect to how these challenges apply to NICU nurses. Gaps in the literature are acknowledged and the significance to the nursing profession is discussed. The search methods used for retrieving empirical literature included internet sources, the University of Alberta's library O*vid* databases, the Cochrane Library, as well as article reference lists. [Key search terms: family-centred care, family-centered care, critical care, intensive care, neonate/neonatal, paediatric, nurse/nursing, perception, experience, nurse-family relation, benefit, barrier, challenge]

Benefits of Family-Centred Care

The benefits associated with the family-centred care delivery model correspond to a high level of collaboration between health care professionals and families. This approach has been linked to improved patient and family outcomes (Als & Gilkerson, 1997; Ensenat et al., 2005; Hendson, Peters, Tyebkhan, Cote, & McPherson, 2004; Hendson, Tyebkhan, Peters, Cote, & McPherson, 2005; Tyebkhan, Peters, Cote, McPherson & Hendson, 2004; Wallburn, Heermann & Balsillie, 1997), which are of a paramount concern in the NICU. Furthermore, more efficient use of health care resources linked to this approach results in a

decrease in overall health care costs (Ramey et al., 1992; Tyebkhan et al.). Research evaluating the implementation of this philosophy has demonstrated various resultant advantages, such as reduced stress and parental anxiety, enhanced learning by parents, and improved parental satisfaction with care (Forsythe, 1998; Walburn et al.). When infants and their families have received family-focused care, benefits such as developmental enhancement, cognitive advancements, and accelerated progress in children with chronic illness have been documented (Als & Gilkerson; Ensenat et al.; Hendson et al., 2004; Hendson et al., 2005; Ramey et al.; Tyebkhan et al.). Improved staff satisfaction and positive experiences have also been observed in response to the promotion of family-centred care (Curley, 1997).

The Realities of Practicing Family-Centred Care

Although family-centred care has been the benchmark of practice over the past few decades, facilitating this integration has been challenging. Proposed restrictions to this practice have been cited in acute care settings, including the NICU (American Academy of Pediatrics Committee on Hospital Care, 2003; Brown & Ritchie, 1990; Bruce & Ritchie, 1997; Caty, Larocque & Koren, 2001; Petersen, Cohen & Parson, 2004; Saunders, Abraham, Crosby, Thomas & Edwards, 2003; Walburn et al., 1997). This highly technical and specialized environment is overwhelming for parents, where advancing clinical and scientific interventions accompanied by rapid changes in a neonate's condition occur at a phenomenal pace. Even though the principles of family-centred care are self-explanatory on paper, the incorporation of these concepts into the daily

functioning of a NICU has been met with restrictions and resistance (Brown & Ritchie; Bruce & Ritchie; Caty et al.; Petersen et al.; Walburn et al.). Furthermore, interpretation of this philosophy is varied, with abundant diversity among facilities claiming to practice this standard (Moore, Coker, DuBuisson, Swett & Edwards, 2003; Sanders et al.). In an effort to improve family-centred care practice, limitations need to be recognized, evaluated and addressed.

Nurses' Professional Identity

Although the philosophy of family-centred care is based on an acknowledgement of the collaboration between health care providers and families, traditionally professionals have been educated within a paternalistic medical model of expertise. This attitude of expertise still exists in the NICU today, where the health care professional is revered as the expert in patient care (Ahmann, 1994; Brown & Ritchie, 1990; Bruce & Ritchie, 1997; Caty et al., 2001).

Interestingly, Letourneau and Elliott (1996) researched the complex nature of the nurse-family relation and suggest that education makes a difference in the implementation of this family-focused model of care. Nurses with university education emphasize more positive perceptions of family-centred care whereas diploma educated nurses are more influenced by the predominantly paternalistic model (Letourneau & Elliott). This outcome was partially attributed to the fact that nurses with university schooling "are normally educated to function in a wider capacity than the acute care setting and therefore not limited to the medical model approach" (Letourneau & Elliott, p.169). With an increase in the number

of degree-educated nurses, will this influence promote family-centred care practice or will a paternalistic attitude persist because of the highly technical environment of the NICU? Although this is an important question, it is beyond the scope of this thesis.

Although nurses recognize the importance of parental and familial involvement in care duties, they report feeling cautious regarding the facilitation of this method of management (Ahmann, 1994; Brown & Ritchie, 1990; Bruce & Ritchie, 1997; Lee, 2004). The knowledge the nursing staff must acquire to be competent with policy, equipment, and therapy in this area is extensive, thus making the role of the health care provider more complex and demanding, especially when the transfer of care duties onto family members is associated with less expertly trained personnel. The nurses describe feeling responsible and accountable for the well-being of their neonatal patients and consequently feel obliged to monitor and supervise the activities performed by family members, to ensure the level of care meets the nurses' expectations (Brown & Ritchie; Lee). Furthermore, successful implementation "may be perceived as a threat to their status as an expert" (Lee, p.39). Brown and Ritchie found that nurses are also concerned with the legal ramifications if something should go wrong when the families provide care. Therefore, the professional's knowledge required to practice in this acute care area has legitimized the paternalistic ideology and minimized collective collaboration with families.

Lack of Required Resources

Nursing staff have reported that they experience constraints in delivering family-centred care, especially in the hospital setting. Not only do nurses claim to be overworked, they feel pressure because they are subject to their own self-inflicted criticisms for not fully integrating this approach into practice (West, Barron & Reeves, 2005). Nurses believe they do not have enough time to perform essential nursing tasks related to direct patient care, let alone address other responsibilities, such as providing familial support and patient information (Hutchfield, 1999; West et al.). Furthermore, the needs of the family are assigned a low importance with the nurse having to prioritize care primarily directed at maintaining and preserving life in the unstable acute care patient (Mendonca & Warren, 1998). Interestingly, when nurses are short of time, giving emotional support is most likely to be neglected (West et al.). Parents of hospitalized children also notice the inadequacies in acute care, reporting that nurses often have insufficient time for families (Ogilvie, 1990).

In the NICU, the parents' lifeline connection to their infant is the neonatal staff, with nurses having the most contact with and accessibility to families. Units reporting low staffing levels with high acuity could potentially experience greater constraints in delivering family-centred care practice. With the increasing availability of reproductive technologies and improved neonatal medical therapies, this is a real concern in an already underserviced field (Johnson, Abraham & Parrish, 2004). Additional research related to staff ratios and acuity to promote family-centred care needs to be conducted.

Organizational Structure

The policies and programs mandated by a health care institution must reflect the family-centred care tenets (Harrison, 1993; Johnson et al, 1992; Moore et al., 2003; Sanders et al., 2003). Furthermore, the administrative commitment in supporting the successful implementation of theory into practice is imperative. With health care restructuring, lack of funding and budget cuts, as well as multidisciplinary professional groups involved in caring for these families, facilitating family-centred care practices has been challenged (Bruce & Ritchie, 1997; Caty et al., 2001). Nurses perceive a lack of organizational support in integrating these principles into everyday practice (Bruce & Ritchie). Furthermore, they recognize that mandating principles of the philosophy without providing the necessary aid in facilitating those elements does not alleviate discrepancies between practice and what is perceived as necessary for facilitating that practice (Bruce & Ritchie).

Lack of Preparedness through Continuing Education

The perceptions and experience of nurses attempting to facilitate family-centred care into practice have been associated with their institution's commitment to provide staff education and skill development (Bradshaw et al., 2003; Bruce & Ritchie, 1997; Caty et al., 2001; Letourneau & Elliott, 1996). Nurses must be sufficiently trained and experienced in their practice in order to adequately teach and empower families (Hutchfield, 1999). As a result, nurses experience an increased need for educational interventions and interactive workshops that would result in further advances in communication skills and

assist in the development of the collaborative parent/professionals relationships required to practice family-centred care (Bruce & Ritchie; Caty et al.). Brown and Ritchie (1990) reported that "nurses' difficulties in meeting their responsibilities towards parents seemed to be compounded by a lack of knowledge in the area of communication skills, conflict management, family-centred care and family empowerment" (p.34). Concurring with this notion of continued educational preparedness; Caty et al. (2001) also found that nurses who participate in pertinent continuing education perceived their practice to reflect a stronger sense of a family-centred approach. Strategies for implementing family-centred care approach must recognize the importance of continual nursing educational support; without these resources in place, family-centred care can not move forward.

NICU Atmosphere

The NICU atmosphere, within the "high tech" nature of critical care, is unlike any other environment experienced by most families. The bright lights and monitoring alarms coupled with frightening sights and procedures, alongside limited direct access to the infants, create an environment that challenges adherence to family-centred care. Furthermore, physical barriers such as isolettes, monitors, intravenous lines, ventilators and other medical paraphernalia contribute to obscuring the direct physical contact these family members desire with their infants. Dobbins, Bohlig and Sutphen (1994) surveyed parents in their perceptions of environmental barriers for facilitating family-centred care in the NICU and found that over half (54%) of the 207 families reported feeling

concerned with the lack of bedside space and privacy. This is the reality of intensive care nursing in the NICU.

In addition, the physical layout of the NICU can either facilitate or hinder the presence and involvement of families (Johnson et al., 2004; Saunders et al., 2003). Success in supporting parents' active engagement in their infant's care is dependent on the environmental designs of the unit. Practices reflecting a family-centred care approach such as breastfeeding, skin-to-skin care and developmental care strengthen "the parents' ability to facilitate their infant's development during their hospitalization and after discharge" (Johnson et al. 2004, p.354). In 2002, a multidisciplinary committee recommended standards for NICU design, with the intent of outlining appropriate environments supporting both the needs of NICU families and the working staff (White, 2002). These recommendations continue to be vital in promoting a family-centred care approach to practice within the NICU setting.

Special Considerations

It must be acknowledged that in the vast majority of cases, family-centred care should be implemented in the constructed norms of the NICU. However, there are times in which this does not represent the best interests of the child, specifically when families lack cognitive and emotional capacity. Furthermore, a family's desire for involvement varies considerably, where not all parents have the same comfort level when participating in the care of their ill infant (Coyne, 1995; Lee, 2004; Sudia-Robinson & Freeman, 2000). In such cases, attempting to build a collaborative relationship requires diversity in the level of cooperation.

Nurses can be faced with daily dilemmas when trying to implement family-centred care principles in an already physically and emotionally charged NICU setting. Understanding nursing strategies for active involvement and encouraging families to participate in caregiving is imperative; however, it is equally important to recognize and accept family diversity in their role of being primary caregiver.

Summary

Although the family-centred care method of health care delivery conceptualizes the importance of family functioning and family development, incorporating this mode of care into an acute care practice setting, such as the NICU, has resulted in many challenges (Brown & Ritchie, 1990, Caty et al., 2001; Saunders et al., 2003; Walburn et al., 1997). Nurturing this philosophy requires the participation of all professionals working cohesively in this environment (American Academy of Pediatrics Committee on Hospital Care, 2003; Bradshaw et al., 2003, Harrison, 1993, Johnson et al., 1992); however, it is the nursing staff that has the most contact with NICU families and ultimately play a pivotal role in organizing care that supports this program in the everyday, twenty-four hour practice. Despite the expanding literature describing the positive benefits of this philosophy, there is a discrepancy between what is promoted as best–practice standard and the reality of clinical practice (Bruce & Ritchie, 1997; Caty et al.; Petersen et al., 2004). Most of the family-centred care literature consists of anecdotal reviews. Limited empirical studies focusing on what the relationship between nurses' perceptions of the identified essentials of family-centred care,

and the extent to which those fundamentals are actually practiced have been published.

Furthermore, the research focuses on mainly the paediatric and adult intensive care populations, neglecting the neonatal group. Although the NICU is a critical care area, this environment differs substantially from even that of the paediatric population. Parents and family have yet to become acquainted with the intricacies of their new baby and possibly face the idea their baby might not survive. Within the paediatric population, the family has already established a knowing relationship with their child. The commitment to family-centred care in neonatal nursing practice still needs to be examined.

Some of the reviewed empirical literature could be challenged today, given the rapid evolution in health care delivery. Neonatal critical care has progressed rapidly over the past decade. One could question whether it possible to fully incorporate this philosophy into the daily activities of the unit. While the perceived limiting factors for implementing this initiative into the clinical setting have been the subject of speculation, they have not been fully researched through the nurse's viewpoint within the present NICU environment.

As the philosophy of family-centred care becomes integrated into acute care settings, continuing research is needed to inform how practice can be concurrently improved. The success of this approach ultimately depends upon the ability of health care providers to understand and support the practice behind the philosophy. The purpose of this study was to uncover the experiences of neonatal nurses implementing family-centred practices within the NICU. By allowing

nurses to share their everyday practical knowledge and experiences, the realities of practice could be further explored and understood. Knowledge gathered from this study will enhance family-centred neonatal nursing care. I now discuss the design and methodology of this study.

CHAPTER III: METHODS

This chapter describes the research method chosen to answer my two research questions. Firstly, what are nurses' perceptions and reported practices in implementing family-centred care in the NICU setting? And secondly, what advice might nurses provide for facilitating a consistent family-centred care approach into practice? This chapter addresses the study design, specifically discussing the qualitative approach of phenomenology. The study setting, participant sample and data collection are elaborated. The data analysis process is summarized and strategies used to ensure rigor of qualitative research are outlined. In conclusion, ethical considerations are presented.

Study Design

The purpose of selecting an appropriate research method is to provide a design that best investigates the proposed research question (Brink & Wood, 2001; Field & Morse, 1985). The nature of the phenomenon guides this process of selection. A qualitative research methodology is most appropriate when the inquiry is exploratory in nature, especially for studying human science relating to the human experience (Field & Morse; Moran, 2002). Various designs have been used in qualitative inquiry such as grounded theory, ethnography and case study methods. Grounded theory lends itself to developing theories about particular social processes where as ethnography research aims to describe culture. Case study focuses on a comprehensive inquiry, often of a single individual. None of these approaches uncovers a range of experience understood by the participants in the same way that phenomenology can do. This qualitative inquiry uses an

interpretive phenomenology research method, where nurses employed in the NICU were interviewed. Specifically, the phenomenon of interest was that of nurse perceptions and experiences with family-centred care practice.

Phenomenology

Phenomenology is a qualitative research approach focusing on the study of uncovering the nature of lived experiences (Koch, 1995; Field & Morse, 1995). The phenomenological approach to investigation is an effective methodology for empowering the researcher to understand human behaviour within the context of social and environmental interactions (Benner, 1994; Lopez & Willis, 2004). Phenomenology endeavours to investigate human experience as it is originally enacted rather than how the experience is imagined to exist. The phenomenological research method does not generate theories or develop generalized models, but provides accurate contextual meaning of the experience (Field & Morse). The study of phenomenology may be descriptive or interpretative in nature. These two approaches to phenomenological inquiry differ in key concepts that guide their respective method of inquiry.

Descriptive Phenomenology

The objective of descriptive phenomenology is to describe the essence of lived experience, with the purpose of understanding a phenomenon as it appears through human consciousness (Koch, 1995; Lopez & Willis, 2004). As the research participants describe their experiences, the process of description and exploration of those lived experiences stimulates conscious meaning (Van Manen, 2001).

An assumption in this tradition is the concept of universal essences (Lopez & Willis, 2004). Simply stated, these essences are the features of a lived experience common to all people that have had that experience independent of its context. These commonalities must be identified so that the description of the original lived experience can be generalized into the correct interpretation of experience, thus "representing the true nature of the phenomenon being studied" (Lopez & Willis, p.728). This approach simplifies reality to its basic facet, removing both history and context (Koch, 1995; Lopez & Willis). It is the belief that essences can be isolated from the original lived experience, and then reconstructed objectively to recreate the experience that holds phenomenology up against the template of a traditional science (Koch 1995; Lopez & Willis).

Fundamental to this methodology is researcher objectivity (Beck, 1994). The researcher must set aside preconceptions and personal biases, to research the pure reflected description of the person's lived experience (Koch, 1995; Lopez & Willis, 2004). This approach advocates "bracketing" or blocking past expert knowledge; therefore, researching the literature on the proposed topic of study is usually not conducted (Lopez & Willis). By eliminating the researcher's preconceived assumptions and prior personal knowledge, the scientific rigor of this qualitative methodology is maintained (Koch, 1995).

Interpretive Phenomenology

Interpretive phenomenology, also referred to as the hermeneutical approach, provides not only on the accurate description of experiences of persons, but also focuses on the meaning embedded in everyday practices (Benner, 1994;

Moran, 2002; Lopez & Willis, 2004). The phenomenon is initially revealed during the process of narrative description and the meaning and explication of the experience becomes unveiled through hermeneutical inquiry (Benner). Interpretive phenomenology is less interested in the factual status and conscious awareness of particular instances than in the significance of the experience on a more fulsome or deeper manner (Koch, 1995).

The goal of interpretive phenomenology is to authentically capture the realities of everyday experiences (Benner, 1994). According to the interpretive inquiry, the meaning and understanding of these practices is influenced by what we already know to be true based on past personal experience (Koch, 1995; Moran, 2002). The historicality of understanding is referred to as being-in-the-world (Conroy, 2003; Koch 1995; Lopez & Willis, 2004). Being-in-the-world not only influences our everyday life experiences but also how those practices are interpreted. In interpretive phenomenology, it is the interpretation of the participants' experiences, in relation to the context of being-in-the-world that is a fundamental tenet.

"Another philosophical assumption underlying the interpretive phenomenological approach is that presuppositions or expert knowledge on the part of the researcher are valuable guides to inquiry and in fact, make the inquiry a meaningful undertaking" (Lopez & Willis, 2004, p.729). Initially the researcher conceptualizes a research question based on a pre-understanding that research is needed in an area that requires interpretive study. The researcher is an active participant during the research process, interacting with the participant(s) through

the interpretation of the data and generation of findings (Conroy, 2003). The experiences and understandings of both the researcher and participant are thus integrated to ultimately produce the conclusive meanings found in interpretive research.

My research question aimed to describe and interpret nurses' experiences and their perceptions of practicing family-centred care within the NICU. This is an important question because there were no empirical studies focusing on a nurse's perception and lived experience of practicing family-centred care within the NICU. By interviewing nurses and allowing those nurses to describe and reflect on their practice experiences, a better understanding of what is practiced was revealed. The interpretive phenomenological approach best addresses this question. Given my extensive NICU nursing background, it was difficult to erase my preconceived understanding of family-centred care practices within this environment. Recognizing this, my past personal knowledge was useful in producing research that was logical in its meaning.

The Setting

The study was conducted at a 65-bed, Level II and Level III NICU at the Royal Alexandra Hospital (RAH). The RAH is a major referral centre for high-risk obstetrical and neonatal patients from northern and central Alberta, northern British Columbia and the Territories. The reported admissions in 2004 were 1244 babies with an average length of stay (LOS) for infants born less than 1000 grams of 64 days (Van Aerde, 2005). In May of 2000, following two years of construction, the unit expanded from a 42 bed unit to a 56 bed unit. The facility

design was completely renovated with expanded private work areas for staff and families, breastfeeding rooms, family sleep areas, sibling activity centers and a parent/visitor lounge. In addition, the unit guidelines were changed which allowed a 24 hour visiting policy for families. Within the past year, there has been further expansion of bed numbers, to the present size of 65.

The Sample

In qualitative research, it is important to select participants based on their experience with the phenomena of interest (Streubert-Speziale & Carpenter, 2003). In non-probability, purposive sampling, the participants are selected based on the "assumption that a researcher's knowledge about the population can be used to handpick the cases to be included in the sample" (Polit & Hungler, 1997, p. 229). This allows for the conscious selection of participants contributing to a greater understanding of the phenomena (Brink & Wood, 2001; Polit & Hungler; Streubert-Speziale & Carpenter).

This purposeful sampling design consisted of staff nurses working in the NICU at the RAH, Edmonton, Alberta (n=5). This sample strategy was chosen in order to obtain comprehensive, diverse, qualitative data. Selection of prospective participants was based on my own knowledge of which participants would potentially provide rich, meaningful narratives centred on various family-centred care thoughts, practices and experiences. Although I purposefully approached potential participants, enrolment in the study was on a voluntary basis.

A total of seven nurses were invited to participate in my study. Two declined involvement for reasons unknown and the other five consented

voluntarily after receiving both the Letter of Invitation (Appendix A) and the Letter of Explanation (Appendix B). Sample recruitment and enrolment was efficient, taking three weeks to obtain all participants.

Inclusion criterion for the participating nurses were: (1) the nurse being a direct provider of nursing care in the NICU, (2) the nurse having a minimum of two years recent NICU experience, and (3) the nurse wishing to share their personal family-centred care nursing experiences. I chose to limit the inclusion criterion to nurses having a minimum of two years recent NICU experience because in this particular clinical setting, these nurses had both secondary and tertiary family-centred care practice. Additionally, it was considered that these nurses would have more family-centred care experiences upon which to reflect. There were a total of 95 eligible full time, part time and casual staff nurses within this unit to choose from.

In keeping with the goals of interpretive phenomenology, it was my desire to obtain comprehensive data, based on meaningful stories of the participants. These experiences provided fertile grounds for interpretation. In contrast to quantitative research designs, qualitative studies work with smaller sample sizes, rendering the narrative data manageable. Generalization of the findings is not the intent of qualitative study (Brink & Wood, 2001; Polit & Hungler, 1997); but rather to interpret common meanings. In review of previous phenomenological studies, thoughtful analysis and meaningful interpretation can be revealed in qualitative designs involving small sample sizes (Benner; Wigert, Johansson, Berg & Hellström, 2006). I limited the sample to five nurses with the

intention to increase the text and data richness by conducting multiple interviews with the same participants. Thoughtful narrative accounts, and manageable data analysis was more salient to the research question than obtaining a large number of nurse participants.

I introduced the study to the selected sample through the inter-hospital email computer system (RAH VAX). After the initial contact, the Letter of Invitation (Appendix A) was distributed to the prospective participants via the inter-unit mail system, further introducing the research project and inviting each nurse to participate in the study. I had access to these mail slots located in the staff lounge. As research participants agreed to be part of the study, each participant was familiarized with the research process (Appendix B). A written informed consent was obtained prior to the commencement of the interviews and data collection (Appendix C). One copy of the signed consent form was given to each participant and the original consent was retained by me. All five nurses remained in the study through its completion and participated in the small group interviews.

Data Collection

According to Antle May (1991), interviewing is the "predominant mode of data collection in qualitative research" (p.188). For this qualitative study, I chose small group interviews as the interviewing structure. "Because interpretive phenomenologists wish to study the everyday practical knowledge and events, the communicative context is set up in naturalistic ways so that the participants do not

feel unduly awkward and constrained by the research interview" (Benner, 1994, p. 108).

According to Benner (1994), the small group interview is an effective method of inquiry that creates an informal atmosphere between researcher and study participants. The nurses are encouraged to talk as they would ordinarily talk to one another, rather than speaking only to the researcher. Furthermore, a small group atmosphere emulates the work environment within the practice setting, further creating a naturally occurring conversational situation among colleges (Benner). Storytelling of actual events will differ from participant to participant; however discussing these narrative accounts among the group stimulates further stories. My role as the researcher was to facilitate the interviews and to listen to the narrations of the participants. This is representative of interviewing methods promoted by interpretive phenomenologists (Benner).

The small group interviews were arranged at the convenience of the participants. At the start, I recognized that this potentially may be problematic because the recruited subjects had different work schedules and worked opposite shifts. With the smaller sample size this was less challenging; however, the coordination of the follow-up small group interview was delayed an additional few weeks for this very reason. A small conference room within the RAH was arranged for each interview.

With the permission of the research participants, the interviews were audiotaped. At the beginning of the initial interviews, I explained the focus of the group session and reviewed the consent form with the participants. The semi-

structured interview process lasted approximately 90 minutes long and attempted to address four guiding, open-ended questions. The four questions were: (1) describe what family-centred care means to you in your nursing practice within the NICU; (2) describe an example where you consistently provided family-centred care in your practice; (3) describe an example where family-centred care might have been appropriate but you were unable to provide it; and (4) what would need to change to allow you to provide consistent family-centred care?

The guiding questions allowed for focused organization but still enabled the participants the ability to reflect on telling their own narrative of perceptions and experiences of practicing family-centred care. During the small group interviews, the participants were able to interact with one another drawing directly on their own experiences as well as connecting with the stories of the other participants. At times, the context of the interview changed as the participants discussed these experiences and uncovered their own meanings and interpretation of family-centered practice in the NICU. As the researcher, I made a conscious effort to allow the participants to tell their stories without interruption; however there were times I probed the participants for more information in areas requiring further clarification. Furthermore, as the interviews progressed, I was prompted to think and expand beyond the initial four questions and pursued answers to other questions. My goal as the interviewer was "to empower the participant to tell the story in his or her own words" (Benner, 1994, p.112). I also kept a personal file of my own interpretations and reflections on my role during the

research process. These notes were used to inform the interpretive process during data analysis.

Each participant completed a demographic data questionnaire (see Appendix D). The basic biographical information collected consisted of the participant's age, years of experience within the NICU and highest level of education. To maintain anonymity of the participants, the demographic data will not be described, except to report that the participants had between five and 28 years NICU practice experience. To assure rigor, the information was reviewed by the study supervisor.

Data Analysis

The purpose of qualitative data analysis is to systematically organize narrative material according to thematic coding (Polit & Hungler, 1997). To maintain the integrity of the data, the researcher must become completely absorbed in the data collected from the research participants (Streubert-Speziale & Carpenter, 2003). Attention to the transcribed interviews and the researcher's personal journal, documenting the process and thoughts, assists the interpretive analysis process.

The data collection and the data analysis process was an interactive process. All the interviews were completed over an eight week time period, from April 3, 2006 to June 1, 2006. All of the interviews were audiotaped and transcribed verbatim by a professional transcriber and by me. Following the interviews, I read the transcribed data while listening to the tapes. To enhance credibility, the audiotape recordings were compared with the written data

transcriptions. As I listened and re-listened to the narrative tapes, I was able to verify the accuracy of the information transcribed onto paper, as well as make notations on the written transcript. Attention to pauses in the oral text, changes in participant voice tones, silences, laughter and sighs were all included in the transcribed written data (Conroy, 2003; Conroy & Dobson, 2005). While listening to the interviews, I conducted a line-by line examination of the written text, noting the responses of each individual participant. Initially each participant was assigned a numerical number; however this proved to be difficult and after assigning each participant a different font color on the written transcriptions, it was much easier to recognize each participant's dialogue. Therefore, I was able to reflect on the "narrative accounts and interpret them based on the background understanding of the participant and" myself (Conroy, 2003, p.4). As the lived experience of the participant's description was read and reread, significant themes were identified through the reflection, conceptualization and categorization of the data (Conroy; Streubert-Speziale & Carpenter, 2003). Clusters of themes were organized into categories according to the formulated meanings (Conroy). Through the content analysis process, essential relationships among the statements were identified, critically comparing and contrasting each category and theme (Streubert-Speziale & Carpenter). During this process I was also able to identify data requiring further clarification. These areas were addressed in the subsequent interview.

The primary focus of the follow-up small group interview was to obtain feedback and verbal discussion from the participants on the thematic data

analysis. An overview of the themes, categories and subcategories was shared with the group, seeking confirmation that what was interpreted was representative of their experiences. This interview also provided an opportunity to seek further data clarification. By returning to the research participants to authenticate the data and interpretation, the scientific rigor of qualitative phenomenology is strengthened (Field & Morse, 1995). Furthermore, as described by Benner (1994), "multiple interviews give the researcher a chance to clarify what was left unexamined in the prior interview" (p.112). Additionally, this interview provided the participants another opportunity to share any further experiences. Following this interview, I was able to go back to the original thematic analysis and make additional notes to elaborate further based on the participants' feedback. The collection of further data was integrated into the analysis process.

As a novice researcher, I worked closely with my thesis supervisor while completing the data collection and analysis. Following my compilation of themes and categories, Dr. Conroy completed a blind reading of the narrative material. We worked as a team during the process of examining, comparing and categorizing the data. Her expertise in phenomenological interpretive inquiry ensured comprehensive verification of themes.

Pilot Study

A pilot study was conducted with me, my thesis supervisor and one selected participant. I selected the pilot study participant from the purposeful sample based on with whom I felt most comfortable with interviewing. This interview provided an opportunity to become familiar with the tape recorder and

to practice effective communication and interviewing skills. According to Janesick (1994), practicing a pilot interview is helpful in testing interview questions and technique. Furthermore, it provided insight as to how I could assure effective use of interview time (Janesick). Additionally, developing researcher rapport with participants is imperative to ensure quality of interview data (Polit & Hungler, 1997). Following the interview, my thesis supervisor provided feedback on ways to further enhance and facilitate an effective interview session. This pilot interview data was included in the data analysis.

Validity and Reliability

In qualitative research, determining the validity and reliability of data is essential in order to establish trustworthiness in the outcomes of the inquiry. Qualitative validity refers to "gaining knowledge and understanding of the true nature, meanings, attributes and characteristics of a particular phenomenon under study" (Leininger, 1985, p.68). Reliability focuses on identifying consistent, accurate and repeatable results (Brink & Wood, 2001). According to Guba and Lincoln (1981), the four major criteria addressing issues of qualitative rigor are credibility for truth value, fittingness for applicability, auditability for consistency, and confirmability for neutrality. Each of these concerns will be discussed in further detail.

Credibility refers to the truth value of the research results (Guba & Lincoln, 1981). In establishing the believability of the research findings, the researcher is most concerned with ensuring the findings authentically reflect the participants' truths (Streubert-Speziale & Carpenter, 2003). Credibility can be

enhanced by confirming with the participants that the results accurately reflect their experience. Furthermore, the transcribed written text must be a true representation of the oral text. During the second small group interview, I presented data descriptions and interpretations of the participants' experiences, verifying accuracy. I also sought elaboration on areas needing further clarification. Similarly, I confirmed that the audiotapes were transcribed verbatim. The study findings were also discussed and verified with my thesis supervisor.

Fittingness refers to the applicability of the results to other situations or settings (Guba & Lincoln, 1981). In qualitative inquiry, the findings may not be applicable in other contexts and the researcher must understand that generalization may not be possible or recommended. Fittingness is achieved when the audience determines a study's findings are meaningful and applicable in terms of their own experiences (Guba & Lincoln). It is not my intent to generalize these research results to other clinical situations. My priority is to accurately reflect the experiences of neonatal nurses practicing family-centered care within the NICU.

Auditability for consistency is the systematic illustration of how the research process was conducted and the results were obtained. Guba and Lincoln (1981) refer to the ability of others to follow the researcher's thought processes, as the research "audit trail". The "audit trail" offers a detailed record of data collection, data analysis and data synthesis, thereby providing peer reviewer's evidence of a systematic research process (Guba & Lincoln). Audibility of

consistency is achieved when other investigators can clearly identify the step-by-step process by which the findings were obtained. I conferred with my thesis committee during the planning stage of the study. I also consulted directly with my thesis supervisor during the data collection and analysis phase to review contextual data. My personal notes were included in the interpretation process, identifying my own thoughts and preconceptions on the collected data. Throughout the research inquiry, there was careful documentation and preservation of data so the findings could be validated by peer reviewers.

The final criterion is confirmability for neutrality. The issue of confirmability for neutrality refers to "objectivity" within the scientific inquiry (Guba & Lincoln, 1981). Quantitative research "objectivity" is often associated with reliable, unbiased and factual data. In qualitative methodology, "objectivity" requires the investigator to be neutral and "dissociate themselves from the phenomena under study by devising a variety of objective extensions of themselves" (Guba & Lincoln, p.126). Maintaining researcher "objectivity" is fundamental to the descriptive phenomenological approach. However, in keeping with the interpretative phenomenology methodology, this criterion of rigor is not an underlying tenet. I was concerned with ensuring confirmability and authenticity of the data and interpretation with the participant. The data, although subjected to the preconceptions of both myself and the participant, was verified for factual experiences.

Ethical Considerations

Ethical standards must be upheld in any research study. "Nurse Researchers have a professional responsibility to ensure the design of both quantitative and qualitative studies maintain ethical principles and protect human rights" (Streubert-Speziale & Carpenter, 2003, p.311). In order to ensure ethical accountability of this study, I maintained adherence to the ethical principles of respect for human persons, beneficence and justice, as outlined by the Canada Medical Research Council of Canada, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada (n.d.).

Prior to the initiation of the study, ethical approval was obtained from the Health Research Ethics Board, Panel B, University of Alberta and Capital Health Region (Appendix E). Further administrative approval was sought by Capital Health, Regional Research and Administration, as well as the Neonatal Research Committee. All potential participants were given a Letter of Invitation and a Letter of Explanation (Appendix A and B) describing the purpose of the study and the research process. As participants agreed to be part of the study and the inclusion criterion was verified, I reviewed the study information letter with each participant and a written informed consent was obtained (Appendix C) prior to commencing both the pilot study and the small group interviews. During the interviews, I again emphasized the voluntary nature of participation in the study. All participants were informed that at anytime during the study period, anyone

wishing to withdraw from participating could do so without being subject to any penalty.

Several measures were undertaken to protect the identity of participants. To maintain anonymity when referring to the participant on paper, a color code was assigned to each nurse. There were times during the interviews where participants would refer to each other by their proper names. This data was deleted and was replaced by "(state's name)". Furthermore, to protect confidentiality and privacy, the interview data was collected and accessed only by the researcher, the thesis supervisor and the professional transcriber. The research participants were told that all research data would be stored in a locked cabinet accessible only by me and that the transcripts, the interview tapes and any written notes would be maintained in this locked facility for five years.

The identity of the nurses participating in this study remained anonymous except to each other and the principal investigator. Due to the data collection method of small group interviews, the issue of confidentiality among the research participants, outside the interview setting, was addressed prior to the commencement of the small group interviews.

The nurses participating in the study were informed of the risks and benefits of participation. In keeping with the goal of the research question, participation in the study will benefit nursing by describing and learning the lived experiences of neonatal nurses practicing family-centred care principles. I believe there were no potential risks involved in participating in this study. Although I am employed as a Neonatal Nurse Practitioner Intern on the same unit, I am not

involved in evaluating the participants' delivery of nursing care and the information provided in the interviews will remain strictly confidential.

Summary

In summary, five nurses participated in this phenomenological research study exploring the experience of neonatal nurses practicing family-centered care in the NICU. Data was collected during three separate interviews; a pilot study and two small group interviews. The narrative data was transcribed verbatim and a thematic analysis was completed. Measures taken to ensure validity and reliability of the data, as well as ethical conduct throughout the study process have been discussed. Their experiences and the thematic interpretation of their stories are explored in the next chapter.

CHAPTER IV: FINDINGS

Entering into the field of qualitative research was a challenging, yet remarkable experience for me. In keeping with the purpose of interpretive phenomenological study, I was able to explore the meanings embedded in the family-centred care practice and experiences of my participants. Although each participant shared their own unique story of their individual experience, collectively commonalities and significant themes surfaced in the narrative data.

The themes have been divided into sections, emulating how the interview questions were set up and approached by the participants. The first section addresses how family-centred care was perceived. Two major categories emerge from this where each participant spoke about advocacy and forming relationships. The second section discusses participants' experiences of ensuring a family-centred NICU environment. Themes derived from this data included consistency of care, and maintenance of a supportive environment. The third section explores the participants' experiences of limitation to practice. The participants were asked to share their perceptions of barriers encountered with this approach to practice and entrusted me with their stories and reflections. The perceived thematic limitations include problems with nurse's professional identity, a lack of essential resources, and inconsistency. The participants' recommendations for improving family-centred care practice in the NICU are integrated into the implications and recommendations for nursing practice section, located in chapter five.

Throughout the data collection and thematic analysis, the transcripts and hand notes were reviewed repeatedly by both Dr. Sherrill Conroy and I. In this chapter, the words of the participants are used extensively [voice inflections in *italics*] so that the findings more accurately reflect their lived experiences. During the interviews, each participant played an integral part in the interpretive process and in defining their understanding of this human experience. As described by Benner, through this systematic analysis, I was able to gain a "new perspective and depth of understanding" while examining the raw data (1994, p.57). While staying true to the narrative text and honouring their experiences, I address the findings emerging from the data analysis.

Meaning of Family-Centred Care

To establish open dialogue with the study participants, I decided to approach my initial interviews by first exploring their perception of their own meaningful reality of family-centred care practice in the NICU. This paved the way for much discussion on what has been historically difficult to conceptualize. The participants' descriptions and interpretations of their perceptions of what family-centred care means in the NICU environment was collectively cohesive. Two main thematic categories emerged: Advocacy and Forming Relationships. Despite being discrete themes, forming relationships and advocacy were so closely entwined that I had difficulty separating subcategories within each theme. At times, while the participants discussed their perceptions of family-centred care, their stories wove between the two categories and at other times the categories seemed distinct. After discussion with Dr. Conroy, it became apparent that the

interview data was not linear, and even though I was trying to reduce the narrative to singular criteria, the data contained plural meanings.

The study participants understood the term "family" as including the immediate family (infant, parents, and siblings) and all other family members significantly involved in the infant's everyday life. In the narrative dialogue, when the participant specifically referred to the "parent" rather than "family", the term parent will be used instead of family.

Advocacy

In the NICU, "advocacy involves ensuring parents have all the necessary information required to make informed decisions, protecting and safeguarding interests, and supporting the parents in their decisions" (Monterosso et al., 2005, p.109). In this study, the nurses viewed themselves as advocates, and their personal experiences reflected accountability for ensuring this; however, advocacy meant going beyond this definition and for these nurses, advocacy often meant "support". Their perception of family-centred care was interpreted to mean support for the infant and the family, as well as for the multidisciplinary health care team. Although the participants recognized the importance of collaboration among these individuals and groups, the theme "advocacy" was subdivided into discrete subcategories.

Family Advocacy

There was considerable discussion about the significance of the family in the NICU environment. Each study participant described the importance of

family development, recognizing that having a baby admitted to the NICU was a difficult and stressful experience to overcome for families.

> [The parents] lose as soon as the baby comes into our unit. They lose something and family-centred care, I believe, is trying to get, maybe not a whole big piece of the something they've lost, but [it is] giving them just a piece…of that role. They lose their role [as parents] when the baby [is in the NICU].

> When [parents] walk into this unit [they] not only lose control because we take [the baby]. We whisk that baby away…and all those hopes and dreams [they] had for that child they've …gone up in smoke because that baby came very early or that baby is very sick.

By understanding the needs of the NICU families, nurses saw themselves as instrumental in providing a family-focused culture in the unit. Incorporating this knowledge was interpreted as pivotal. One nurse described her philosophy of family-centred care to mean:

> *Empowering* the family…Respecting who they are, what they are bring to the unit, their religion, their culture, their whatever, their ethnicity, their sexual preference, what they are bringing. I feel…it is important that we respect that and we *allow* them to do for their infants whatever they can that will help them bond with [their baby].

Support for the parents and family was multifaceted and closely linked to recognizing both the dynamics of the family unit and the vulnerability of the family members. One participant emphasized that involving the family meant advocating for the significance of the parental role recognizing the parent as being the constant in their infant's life:

> It is important to add the mom and the dad in there or just the mom or just the dad or whatever, because they are the ones looking after this baby after the baby goes home so you want them to be able to do that the best way that they can.

Thought to be fundamental in establishing a family-centred care environment was making it explicitly known to the families that they were welcome to become active participants in their infant's care. This collaborative participation was under the direction of the health care staff and the study nurses understood their role as "helping to support [families] along this process". Parental involvement in care was essential for both the healthy attachment and the optimal development of the NICU infants. This significance was verbalized by one nurse who stated "involving the family…[is] less stressful for the baby and easier for the family". Although these nurses perceived they fostered parental participation, the participants verbalized that parents needed to be "openly" invited to participate in their baby's care, understanding that this phenomenon was not implicitly recognized by parents as a given. An "invitation" required the demonstration of welcoming behaviour to the vulnerable family. Informative, open communication between the family and the health care professionals encouraged families to make informed choices for their infants.

> Offering [parents] to go to rounds. [Help them]…feel like they have some control and they are very involved with their baby in that way, in rounds. Because that is very important. Sometimes they need to be invited, [the parents] don't know if that is something that they can do…That's an important part [of their role as parents].

Included in advocacy for the family was the participant's experience of providing educational support for parents. Teaching families and information sharing was thought to be integral in facilitating family involvement. One nurse described "helping them [parents] learn, teaching them, helping them interact with their baby, [to] be a part of the team that is making the decisions". Disseminating

vital information was recognized as being crucial and the nurses felt their professional expertise was essential in that process. When asked who the participants thought were the best people to have the connections with parents, the response was "the bedside nurse…[we are] usually the first person they speak to". It was known that nurses provided continual unit coverage, seven days a week, and were fundamental in sharing information with families. Although other disciplines are involved in health care delivery, the study participants thought that "helping the parents to figure out their own baby's cues, so they can get to know their baby the best and then be the best advocate of their baby" was facilitated primarily by the bedside nursing staff.

Additionally, it was perceived that the nurses were the ones who were "there for [the families] everyday so that [the parents] could have their questions answered". Equally as important was the participant's understanding that nurses spent the time "making sure the parents understood what was going on" by providing educational support. Ongoing involvement and supporting communication was felt to be necessary for parents to be partners in care and these nurses perceived they were in a strategic position to have a positive impact.

Family advocacy requires that families are involved in their infant's care. Teaching parents and information sharing was associated with and essential for providing support for the NICU families. Even though providing this support was thought to be integral in facilitating family involvement it also required the establishment of collaborative relationships between the families and the health care providers. This thematic category will be explored further on in this section.

Infant Advocacy

The study participants engaged in the exchange of perspectives and interpretations about what family-centred care meant in their scope of practice. As the nurses spoke of being involved with the infant's care, supporting the family was integral; however their words often segregated support for the infant from advocacy for the family. Infant advocacy was viewed as a fundamental role of the NICU nurse. When one nurse was asked about how she perceived family-centred care to apply to her, she replied:

> First of all, family-centred care for me, it means looking after the baby. Number one, being an advocate for the baby and looking after the family…You have to involve everybody in that piece…You are on their team to help make decisions [about] what's best for the baby…You are trying to look after that baby as much as you can when you are at work or [to] be there for that baby whenever you can.

Although each nurse recognized the positive experiences associated with family advocacy and acknowledged that the neonates benefit from having their families present and providing care, these nurses expressed a high level of responsibility toward their patients. One participant stated: "as much as we are here for the parents, our number one priority should be for the babies' care". Strong emotional feelings of infant advocacy were described by some participants when there was parent-staff interpersonal conflict resulting in concern about parental treatment decisions.

Some participants spoke about attempts to exert control over situations and advocate directly for the baby in times where their perception of what was in the best interest of the infant "clashed" with what a parent's choice regarding care and medical treatment of their infant. As described by one participant, when

referring to staff "doing whatever parents say…", questioned her own meaning of family-centered care by stating, "but, [sometimes] that's not necessarily the sign of the best thing for the baby". The reply by another nurse: "and that brings me back to the point of my focus is that baby. That is why I am here".

While these participants indicated that supporting the infant was a major focus in their role as practicing NICU nurses, their dedication to the families in providing support and advocacy was additionally meaningful. Showing collaborative behaviours towards parents and families was also imperative even though some of the participants expressed that they were far more comfortable, and less emotionally strained, fulfilling their role as an infant advocate.

Staff Advocacy

Much of the family-centred care literature focuses on the importance of supporting the family well-being by promoting parental presence and active participation. According to Harrison, "consumers, working in collaboration with professionals, can exert a powerful positive influence on the provision of medical care" (1993, p. 643), care that reflects the family-centred care tenets. In addition to supporting the infant and family, the participants understood family-centred care to also incorporate "advocacy for themselves".

One nurse spoke about how NICU nursing is very "task oriented" and having extra staff to "help to listen for [monitor] alarms" alleviates workload. She explains:

> …just [someone] coming into your…[room] and listening for alarms so you can just sit and spend some time with your family. Or maybe do that one assessment for you that you need to get done…If you get

> somebody else to do it for you then you have more time to spend with your family. Just to help you get your workload done.

Special to the RAH NICU is a position called the "float nurse" which was implemented into the nursing care assignment in the past few years. This was in an attempt to ease the strain of nursing time and manpower. This supportive measure has been an asset for the bedside nurses and recently, a second float nurse position has been added to the nursing schedule to help with the daily activities of a busy unit. As one nurse explains:

> I think [the float nurse helps]. I think it does. I think that people have to remember to lean on the float so that they can organize their time to do that. The [nurses] are so task oriented to get these certain jobs done…like going for tests, transferring babies, starting IV's, you know those kind of things…You have to remember that the float is there to do that too. Now we have two floats so it should help a lot.

In communicating their perceived needs, these nurses spoke of experiences where they desired multi-professional support to practice this philosophy. As one participant explains: "what I think needs to change is support. [Support] from medical staff, nursing staff, [and] from social workers". This statement was in reference to their interpretation that it is nurses "carrying out the majority" of family-centred care practices.

> … The managers leave at 4:00 p.m., the social workers leave at 4:00 p.m., besides the person on call that has to deal with all the issues of…[the NICU] and all or most of the physicians are gone by 4:00 p.m. and it's the *bedside nurses* who are at the bedside 24/7. What I find sometimes [it] is…a social worker or a physician or a unit manager will make a comment, or…a suggestion to the bedside nurse to carry out certain things that would encompass family-centred care and then they walk out of the room and their five minutes at the bedside is up, and then it's up to *us* to carry out…the things, what's expected of *us*…

One participant offered her thoughts saying "if we're going to look at family-centred care…the nurses are a huge part of it, and [so] the nurses should start having more say". Her desire for nurses to have a greater "voice" was particularly aimed at the facilitation of a more positive experience for all involved members. According to Bradshaw et al. (2003), a key strategy in the ability to practice family-centred care effectively is to learn with and from each other; however, the nurse participants honestly discussed their perceived feelings of lack of overall support. As they worked through their frustrations in the interview sessions, they were able to discuss ways they felt would improve collaboration, shared learning and clinical applicability. These will be discussed in the final chapter.

Forming Relationships

A fundamental tenet of family-centred care practice is supporting the full involvement of both parents and families. In the NICU, advocating shared participation involved the development of supportive relationships between the families and the health care professionals. The study participants acknowledged these relationships to be collaborative, respectful and trustworthy.

The Collaborative Relationship

In fostering a family-centred care environment in the NICU, both the parents and significant family members must be active partners in the infant's care. Developing collaborative relationships is crucial in supporting this care-giving role and in creating an environment less stressful for the families. As one participant vocalized "if you are lucky enough to go down to the delivery [room]

then you get to meet the parents right away, talk to them, [and] form a relationship right there, right even before the babies are born". Another participant reflected:

> I think when the baby is first born, right in the first few days when the baby is [the] most unstable, it is important that [the families] establish some kind of relationship with somebody so that it is less stressful for them right from the beginning and then they [the families] feel like they have somebody who is listening to them and who is looking after them and who is caring about their baby. I think … [this is] *really* important.

These nurses perceived a family-centred care approach to practice embraced a collaborative partnership between staff and families. Forming that relationship provided a perspective where families "felt like somebody cared about them, someone's listening to them". These opportunities were felt to facilitate parental connection with their infant and altered the "stress level" experienced by the parents. The practice to support collaborative interaction and participation has changed over time, where the emphases to facilitate a more family-centred care approach has been implemented. As one nurse reflected:

> I come from a *long* background of neonatal nursing. I have seen an *incredible change* in the way it [used to be]; most people did not hold their baby 25 years ago, whereas it is one of the first things we do now is try to get the parents involved, the bonding thing. We knew about bonding 30 years ago, but did *we* do anything about it? No. Those parents did not hold their babies while [their baby] was intubated, [and] most of [the babies] were intubated for 6 months with chest tubes.

Another nurse elaborates on this phenomenon:

> You know when I first started in the NICU, the babies were really, really sick, but we didn't have what we have now to look after them…So they do better now but they are more chronic. You've got your babies that are here for a longer period of time because we are saving more babies at an earlier gestation, which means that they have

> to be here a lot longer and the families are more involved and that makes it busier too because back then the families weren't really welcome to be involved. So it was just do your work, you know, without having to do a lot of breastfeeding teaching, which takes up a lot of time trying to get [these babies] to breastfeed. Yeah, parents are more knowledgeable now, they want more information, so it takes more time…Before I don't remember ever sitting down with a family and going through bronchopulmonary dysplasia. We just didn't do that, you know. [The families] came, took a picture and left. They didn't even hold their baby usually for weeks and weeks. Kangaroo care wasn't a part of nursing when I first started in the NICU. That came several years later and it took many years to get used to the idea of kangaroo care…Certainly no '24 weekers' were being held in kangaroo care that were intubated. Parents did not hold their intubated babies.

The nurses also spoke of the importance of creating situations where they took the time to form these relationships with their patients and the families. Although "spending time" with the families was perceived as "taking a lot of extra work" in an already busy unit, the nurses understood its significance in "offering the family, family-centred care, by definition". This expectation was identified as a requirement to be practiced by all health care disciplines working in the NICU environment; however, some nurses felt only their profession actively supported this approach.

> It starts off by just introducing yourself and letting [the family] know your name, and I am going to be here from 7:00 a.m. to 3:00 p.m., looking after your baby and this is what our plan is for today,…[and] what is your plan for today?...It is just sitting down in a chair beside them and just spending five minutes talking to them, which usually turns into an hour…and then you are stuck there for an hour, but those are the important things. Everybody has to do that…Everybody has to take the time to talk to [the family] and explain things to them.

One nurse spoke about understanding the NICU environment and explained how important it was to relate to both the parents and extended family. Vital to being able to practice this approach, one must create a caring

environment, fostering positive interpersonal relationships. From experience, one nurse explains:

> Having empathy and sympathy for them, which is understanding where they are coming from. Helping them keep calm, cool [and] collected. I understand that because I have been on the other side of that as a parent, of a sick child, being in the hospital...I understand what it feels like to be in that predicament…Just having somebody that cares about your child just means everything. It makes your hospital experience so much better.

Trust

Developing this rapport meant establishing trust between staff and families. Trust was felt to foster an environment that supported all who were involved in the relationship: the infant, the family and the health care professional, specifically the staff nurse.

At times, it was felt that certain experiences negated a trusting relationship and nurses would make attempts to advocate for collaboration, but only to a certain extent. This difficulty presented when there was a control issue and nurses perceived that parents were questioning the nurse's expertise and knowledge. One study participant spoke of an experience where, during medical rounds, a parent inquired about the appropriateness of a nurse's judgment in practice. This participant was angry that the parent's concern was not discussed directly with the nurse involved and the incident was discussed "behind the nurse's back" in medical rounds. She stated "I interjected [in rounds]…and said 'you know, actually the nurses are a good resource person to evaluate your baby's status at that time and you should actually trust what your nurse says at that time'". This participant felt she needed to verbalize the importance of reciprocal trust and

questioned "how do we get …[the families to]…trust what we say?" This nurse was seeking to improve mutuality in the development of the trusting relationship. "The closeness of the relationship is negotiated by the professional and patient and both are recipients of gifts of care, concern, satisfaction and wisdom" (Titchen, 2001, pp. 74).

Respect

The study participants were keenly aware of the importance of supporting respectful interactions with families. Their experiences solidified how reciprocal respect enabled the relationship to flourish, building on the strengths of the members and acknowledging a true partnership. Another nurse interpreted "family-centred care [to] involve…respect for parents no matter what". Although formalizing this mutual respect took time, it was a nursing priority. As explained by one participant:

> I was involved in primary care… I formed a very close relationship with the parents. They were very intelligent, very questioning. I think we respected each other in the sense of I respected what they thought what was best for the [baby] and they also respected what I would say to them…I also got to the comfort [level] where I could tell the Dad 'O.K., you're here, you need to go home and sleep because I'm here to take care of [your baby] the rest of the night. If you want to call me, that is fine, but right now, you need to do something for yourself'.

In summary, historically the NICU environment was designed to support the medical needs of the infants. Today, the family-centred approach to practice emphasizes a partnership between the families and the health care professional to benefit the optimal development of the NICU patient. Based on the practice experiences of the study participants, family-centred care meant supporting advocacy and forming collaborative relationships. Although family-centred care

has been promoted as the standard of care for families and infants in the NICU, implementing this approach has required innovative practice initiatives. Below, the participants explore their experiences of providing family-centred care.

Providing Family-Centred Care

Globally, NICU nurses have been expected to practice under the conceptual framework of family-centred care and the NICU nurses at the RAH are no different. After the study participants at the RAH explored what family-centred care meant to each of them, they began to share how their practice experiences reflected this approach. Their understanding of how the concept is applied in the different care levels of the NICU was examined. The elements of nursing practice included consistency of care, and the maintenance of a supportive environment with respect to health care delivery, patient visitation and unit design. Each theme will be discussed separately; however all of the categories and subcategories were closely interconnected.

Consistency of Care

"During lengthy hospitalizations, families can become attached to and dependent on the NICU staff" (Ritchie, 2002, p.78). For this reason, any infant and family at the RAH, likely to have a complicated NICU course, is often assigned a primary care team. Establishing primary care teams can enhance the development of respectful, collaborative partnerships between families and the NICU staff and help alleviate some of the distress experienced by families.

At the RAH, primary nursing care teams comprise consistent nursing personnel responsible for caring for the infant and the family throughout their

entire hospital stay. This approach can lend itself to incorporate family-centred care but is not limited to it. As one participant describes, caring for the infant and family includes "looking after that baby as much as you can when you are at work or be there for that baby and for that family whenever you can" in spite of provide providing direct care also to other NICU infants.

During the interviews there was much discussion about primary nursing and primary care teams. Presently on the unit, only a select number of infants are under the direct care of primary nursing teams and most teams comprise only four to five nursing personnel per infant. This is a voluntary nursing practice and the process to identify infants and families in need is primarily under the direction of nursing management.

One nurse used the words "*out of their tree*" for describing parents "*really stressed*" by their NICU experience. She explained that the consistency of providing the same nursing assignment, the same information and establishing a trusting relationship between the primary nurse and the family provides a less stressful environment for these families.

> …the parents really need that type of nursing. It is not an automatic thing here to think about primary care teams… Usually after a few weeks, after the baby has been here a few weeks, [and by] then [the parents] are already *out of their tree*. They are just *really stressed*. Unless [the parents] are out of their tree, that is usually who gets the most attention, the *high needs* babies and the *high needs* families. Their baby could be well and they are not coping…It depends on the dynamics of their family, but most often it is usually the *high needs* parents that get the primary care teams.
>
> …It is important to have consistency for the family, not only for the baby but for the family too. Pretty hard to do on this unit when you have 350 staff members working, but I think especially for the babies who are really sick, they need that. [They need the] team to be there

> for them to help make the same decisions. The *same* people talking to them telling them the *same* information, making sure that they are getting enough options, not just one person's on how [their NICU stay] should go. Just ... [looking after] the baby whenever you can. To be the consistent person that knows the baby, [you] can see the differences in the baby…If the baby is getting sick, then you are going to kind of hopefully know that. Portray that to the people who are looking after [that baby]...

In facilitating a collaborative environment, designed to support reciprocity, all members of the primary team work together to develop a knowing, therapeutic relationship based on trust and connectedness with the infant. The infant's typical idiosyncrasies and behaviours are cohesively observed and participation in care-giving provides emotional and social comfort for families.

The study participants spoke of their primary care experiences, highlighting the complexities involved in providing primary care teams for all NICU infants. One participant identified herself as a "strong believer in family-centred care and primary care and…I believe that family-centred care requires primary care teams". Another participant interpreted the same need for level of support for primary nursing but added:

> I think they need to set guidelines…to start off because it is not an automatic thing that every baby gets primary care nursing. I think we are all supposed to supply family-centred care to every single baby that is born [and] in this unit. So, it's not just primary care nursing; it is the whole [approach where] we're helping to support you along this process, you and your baby it does not mean you are going to get the same nurse everyday. It is hard to…like the concept of family-centred care should always be there, no matter if you have a primary care team or not, but I think the best way to do family-centred care is to have a primary care team.

The study participants spoke of enhancing their ability to provide care that was truly family-centred. As primary nursing care teams are established in the

RAH NICU, the participant nurses felt they wanted to be more assertive in establishing guidelines to facilitate this approach. By providing consistency, they interpreted primary nursing as achieving a greater understanding of infants and promoting communication with families. Furthermore, the participants interpreted their role as primary care nurses as bridging the attachment bond between the infant and the family.

Supportive Environments

Neonatal Individualized Developmental Care and Assessment Program

With the goal of optimizing the long-term health and development of the NICU infant, a relationship-based developmentally supportive approach to newborn intensive care has emerged (Als & Gilkerson, 1997). This model of care is called the Neonatal Individualized Developmental Care and Assessment Program (NIDCAP) and its clinical implementation at the RAH has been instrumental in bringing about a multidisciplinary change to practice. Individualized, supportive care is geared towards building on the strengths of each baby and family, where behavioural observations of the infant guide how neonatal intensive care is practiced.

> Developmentally supportive newborn intensive care has been defined as a professional alliance, that supports the parents' engrossment with their child and the child's neurobiologically based expectations for nurturance for the family, an alliance that listens to the language of the infant's behavior and uses the dialogue between the infant, family and professional caregiver to guide care (Als & Gilkerson, 1997, pp. 178).

As one nurse explains how NIDCAP "fits" in the context of providing family-focused care in the NICU, she reinforces:

> NIDCAP certainly supports family-centred care because that [family-centred care] is a big part of NIDCAP nursing; I think that is why we could call this [unit] a family-centred care unit because we have accepted NIDCAP as our part of the way that we look after our babies.

One participant describes parental participation during a NIDCAP assessment. Her experience of focusing on the infant and building on a collaborative relationship with the family provided her a sense of pleasure and positive reflection. As she explained, she spoke with honourable pride:

> The first part of …doing an observation is you get to watch the baby for 1 hour to 1.5 hours to see how the baby reacts to the environment and how they react to people's handling and hopefully it's done while the parents are there so that you can see how they also interact. How they are involved with their baby. You document all that and you sit back and you kind of try and make a plan according to what your observations were, to what the baby has done, to make it less stressful for the baby and easier for the family. So I get a whole day to do that and in that day I get a couple of hours at least to talk to the family. We go through everything from the top of the baby's head to the bottom of the baby's toes and try to get maybe some of the questions that they are too afraid to ask. I get to really understand how [the parents] are understanding things. [I] try to get them all the help that they need so whether that means they need to see a doctor or they need questions asked that I don't think they are understanding…I give them…lots of readings with pictures so that they can actually have that visual part of it and see how that works. I go over my data that I put on my pages so that it kind of actually helps them see 'this is what your baby did in this hour' and it is on paper to help them deal with that and with what the nurses do…You go over your observations, you make your recommendations and then you go to the family and you go over these recommendations and you see just by talking to them, they have usually something to add to the recommendations from what they have seen. Maybe they don't recognize it as this is something that their baby likes or doesn't like and then you can kind of articulate for them and add it to your recommendations so that [the family] feels like a part of their baby's care and help them make decisions for their baby….that part is really good for me…[with being a]…NIDCAP nurse…I get to be really involved. Especially with those babies that I do NIDCAP on so I get the time made for me to do that, where other nurses don't get that.

NIDCAP was first introduced to the RAH staff seven years ago when a randomized control trial was conducted in the NICU. High-risk, very low birth weight (VLBW) infants were randomly assigned to two groups; one group received standard NICU care and the other received NIDCAP-based care (Tyebkhan et al., 2004). Fifty nurses volunteered to receive a one-day introduction to NIDCAP education and training including what NIDCAP meant and how to support kinder, and gentler nursing care for the babies. The results of the study recommended that NIDCAP become a standard of care for all very low birth weight infants (Tyebkhan et al.). All five of the study participants taking part in my qualitative study were employed in the NICU during the NIDCAP trial.

The RAH NICU currently employs trained NIDCAP observers, with more individuals in the process of completing their training. A NIDCAP observer is responsible for completing neonatal observations, and formulating and updating care plans. During the small group interviews, the process of change to implement this concept of care was described as being a "slow process". One participant mentioned the need to train more NIDCAP observers and to certify a unit-based NIDCAP trainer. The RAH NICU is currently in the process of providing informal hour-long educational opportunities for all staff nurses in the attempt to increase awareness of the NIDCAP framework. The essential training of its clinical application and linking the conceptual piece to clinical nursing practice still needs to be organized.

Although the implementation of NIDCAP continues to evolve, the participants realized that the service it provides to families is optimal. One nurse

reflected that parents "love it…and it does help. The babies do better, they do get out of here quicker and there is just more support for them. [For both the families] and for the babies, you get to know them really well, so it helps".

Unit design

While the mainstay of family-centred care in the NICU focuses on building partnerships between health care professionals and families, the operational infrastructure and design of the unit helps to facilitate its successful implementation. Being able to support family-centred care practice entails NICU designs that provide the necessary medical equipment to care for the infant, yet also provide an environment to allow the family to establish their relationship with their baby.

During this study period, there was both increased patient census and acuity with the unit occupancy ranging between 90-110%. There was an average of 62 babies in the unit each day. Each room or pod, on the unit accommodates between six and nine babies, depending on whether the infant is on the intensive versus the intermediate care side of the unit. The intensive, Level III care design offers extra space at the bedside to allow for the additional equipment required to care for the critically ill infant. All bedside spaces have privacy curtains and all pods have natural lighting with windows.

There is also support space for families. A parent lounge equipped with television, kitchen facilities, a child play area and lockable storage is available for all NICU families. There are also sleeping rooms for mothers who wish to stay at the hospital in close proximity to their infants, two parent rooms for overnight

stays and two parent suites for out of town families with critically ill infants. Additionally, support groups, sibling play groups, and educational information sessions are provided for all families. A lactation room as well as equipment for expressing milk at the bedside is readily available for mother's use.

Prior to moving to the newly designed NICU in 2000, the previous RAH unit did not facilitate the presence of families. The unit design did not provide privacy, nor did it provide adequate space to allow comfortable workspace for health care workers and visitation space for families. There was restricted visitation, where the parents were only "allowed" to visit between preset hours and were not invited to attend the physician-led patient rounds.

All the study participants worked in both unit environments and as one nurse describes, her experience reflects a more family-centred approach in the newer unit.

> …[family-centred care] is important to me, our unit is set up different now so we're in a pod, so it's got more privacy and you're more able to [practice family-centred care to] do it, there's more space for the parents to even just be there with their baby, because on our old unit that wasn't really possible. There was no room for them to be there, they were always in the way. I think our unit is definitely busy compared to what it was before but it is a different busy.

> …I think [of] the support group we never used to have those for parents, there is just more [family-centred care focus], it's just bigger, like we're a multi-system team with many layers of this and that going on that we don't even know what goes on because it is just, it is just bigger. It's like a huge corporation 'NICU nursing'

By virtue of promoting consistent family-centred care, facilitating parental presence and involvement in caregiving and decision-making, the study participants understood what basic features were required in unit design.

Although they commented on the importance of meeting families' needs, they too spoke of being active stakeholders and of their desire for efficient, convenient workspaces. This was echoed in their discussions regarding the family visitation policy.

Visitation

An essential element in fostering family presence in the NICU is providing for unrestricted family visitation including both the immediate and extended family visitation privileges. "True family-centered care requires that parents have unlimited access to their infants, meaning that they are not excluded from the NICU during rounds, report, admissions and emergencies" (Griffin, 2006, p.99). The workplace culture must reflect an atmosphere that welcomes families. The initial parental exposure is often initiated upon the infant's admission to the NICU and the nurses considered this essential for minimizing stress for the anxious parent.

The current visiting policy, revised in 2003, encourages unrestricted parent and sibling access to the infant. Additionally, parent inclusion and participation in physician-led rounds is supported. The parents are also able to authorize other family members' visitation; however, these "surrogate visitors" are not entitled to any medical information.

As experienced by the study participants, there was intense discussion about the current visitation policy. One participant interpreted the "visiting policy" as "important. It's a good one", whereas other participants ideally wanted the current policy reviewed. As stated by one participant, "the visiting policy was

put into place to support family-centred care but if it is not doing what it needs to be doing, then it needs to be [changed]".

The perceived lack of consistency with respect to adhering to the visitation policy was discussed among the study participants, where the limitations for nursing practice were identified. Parental presence was understood to be vital in fostering parental involvement; however facilitating an environment for "surrogate visitors" was identified as a challenge and the study participants were concerned with "breaching confidentiality". The nurses acknowledged concern about their professional accountability towards the parents and the infants when visitation was extended to the significant family members. They were "gatekeepers" and at times this was a frustrating experience for the participants.

> I don't think we're doing the parents a favour when the baby first comes in the door, to have family member X, Y, Z, L, M, N, O, P come into the unit when they're not there. [Initially the parents]...think it's great because there will be people to cuddle their baby, and this is all fine and dandy while the mom is still recovering and stuff. And then, if you talk to some of these parents two weeks later, they're really *sick and tired* of the amount of visitors that come. The amount of family members that are here when they're not here. The amount of family members that ...somehow acquire...[medical] information...when they were not here...Once again, the [parents] are losing control.

Additionally, the number of visiting people at the bedside was an associated issue for the participants, although this "frustration" did not apply to parents and siblings.

> I find it extremely *frustrating* to have more than three people at the bedside with me there. To me, that's a *huge* frustration. I don't mind if we have three brothers and sisters and the parents. That doesn't bother me, but when you bring in aunts and uncles and grandparents in, and now there's five people at the bedside and I have to try to work around them...

In summary, fostering family-centred care practice was interpreted as promoting consistency in caregiving and facilitating a supportive environment that promoted the concept. The current unit design and unrestrictive visitation was identified as vital in family-focused health care delivery. However, through the appraisal of their family-centred care experiences, the nurse participants acknowledged limitations in their ability to fully enable and practice this philosophy. As a consequence, the nurses' enthusiasm to promote the practice was diminished.

Limitations to Practice

As health care professionals promote strategies to practice in a family-centred care manner, specific attitudes and practices sometimes fail to reflect commitment to such involvement (Rushton, 1990). With the study participants' experiences, there were perceived events where uncertainties in practicing this approach were described. In the following paragraphs, the participants' understood dimensions of practice barriers are discussed; the nurse's perceived professional identity, a lack of essential resources, and inconsistency. As stated by Rushton, "a careful examination of the barriers to family-centered care is necessary before it is possible to identify strategies to achieve this goal" (p.69).

Nurse's Professional Identity

Although the family-centred care practice approach is based on the acknowledgement of building collaborative relationships between health care providers and families, the study participants described experiences where creating partnerships was impaired. Some participants' practice was dominated

by an expert-driven model and other participants communicated daily constraints in their attempts to facilitate partnerships with families.

During the interviews, as the participants pondered over what family-centred care meant in the context of their nursing practice, their experiences reflected a varied interpretation of the philosophy. Although they communicated that advocating for the family and building collaborative relationships was vital to providing a family-centred care environment, their practical experiences suggest otherwise.

Professional Expertise

At times, some participants struggled with creating reciprocal partnerships, especially during times when families questioned their professional expertise. The partnerships were obtusely observed as "mutual" when the families demonstrated compliance to the ready-made medical plans and interventions. Occasionally, some of the participants spoke as if they were unilaterally defining the role that parents should be "allowed" to play in decision-making. If nursing or medical decisions were questioned, a perceived "lack of knowledge or understanding" was assumed and collaboration was compromised. As one participant perceived:

> If everybody…came to some consensus to make the parents feel... "empowered" without *us* looking like the bad people that are trying to take away the parent's right, [practice would improve]. But we do have the knowledge…to make decisions sometimes that cannot include exactly a parent's decision. They can be part of the conversation but what is happening sometimes lately is parents think that they should be making some of these decisions and they are not *listening* to the information that is being given to them…What is the point [at which] parents have the right to say…that they have the choice about certain things on the unit or the input versus other areas

> and I think *that* is the issue sometimes. Some parents come in here and think that they really have the choice whether their child should be intubated or not.

For some participants, collaborative decision-making was an issue when the status of the infant was considered unstable. These participants understood that full parental participation in medical decisions was a viable option only if the staff felt reassured by the decisions made by the parents. The collaborative decision-making did not extend to examples where the infant's condition was deemed critical and the parent was perceived to be making decisions based on their own fear about their infant's survival. As a result, advocating for the infant's best interests in keeping with their professional expertise was protected.

> There are certain things that parents should have a say in and I believe…if it involves medical care or nursing care, there has to be a limitation in the sense, [the family] can't tell us what they think we should do…medically because no matter what their education background is, are they truly trained in neonatology?...I don't know where the limitations should be [or] how you define that.

> This is a medical place, and I just think that there are certain things that have been happening where…the parents [feel like they are able to make decisions]…Are the parents, in that crisis situation, able to make some of these decisions?...Probably not, but they think they can.

> But [families] sometimes have a clouded judgment…Well on the side where the kids are getting closer to going home…the parents need to be more involved right? I mean the mother if she is breastfeeding, they can come in and do the baths…they have gotten to know their babies a little better in some cases. I mean some of our babies who have been here longer, so now is a good time for [parents] to take the baby out; they learn to read their baby's cues more; they're more independent in holding, changing…But, some of these parents think that, when you have an unstable baby on the other side of the unit they think that they can make those decisions at that time…

This thinking was not upheld by all participants and practicing this approach was understood to be essential regardless of clinical situations.

Understanding the family dynamics and the strain on "parenting in the NICU" was identified as evidenced by one nurse's explanation:

> ...my thinking is eventually they are the ones that are going to have to take the babies home, so if we make a decision for them and it turns out to be a decision that causes some sort of problem with the infant and they're not involved in making that decision, then what we are doing to that family is literally putting our beliefs or what we think is right into their family system.

Even though the study participants understood the need to engage in collaborative relationships, they acknowledged situations where a perceived lack of professional respect precluded their desire to practice effective family-centred care. This was heightened by the participant's pre-existing knowledge and experience with "difficult families". It was noteworthy that escalating power struggles or persistent interpersonal conflict reinforced a professional hierarchical position over the family.

Role Confusion

As experienced NICU nurses, the study participants spoke about the various nursing roles in the NICU. They struggled with personal role conflict and role ambiguity. In practicing family-centred care, role conflict augmented frustration for the participating nurses.

Nurses having more than two years clinical NICU experience are considered "experienced" nurses. These staff nurses work "bedside", complete charge duties, volunteer on primary care teams, mentor and preceptor new staff and students, actively participate in the many NICU committees, and train for specialty roles, like NIDCAP observers and lactation experts. As one participant explained "for someone like me, that does a little bit of everything...It's hard for

me to stay just as a bedside nurse, so I kind of struggle with that a lot". Role conflict was a source of added strain, especially when their priorities conflicted with the operational needs of the NICU.

> …either you [are] doing something else [other than direct patient care] or right now it is very busy with priorities being set so…you have to be pulled to do charge and you can't do your primary care nursing or there is preceptorship and mentorship [nurses] that need to [be assigned to] that baby so then your own priority is on the bottom again.

Furthermore, the study participants identified role ambiguity as limiting family-centred care practice. Their perceived desire for role identity involved "consensus" within their own profession, among the various roles of other health care professionals, and the role of the NICU family. By comparing experiences, the participants questioned who should be "the ultimate decision maker" for the infant's medical care. During instances in which some of the participants perceived a need to "protect the infant," the nurses questioned if "active" involvement of the family and the family's "role" was associated with "control conflict". As a consequence, power and a mismatch of caregiving goals resulted in the devaluation of the needs of the infant's family members. Perceived role conflict was closely interconnected with the need for essential family-centred care education.

> I think what it comes down to is…defining the *roles* that each of us play in [family-centred] care,…the family's role versus the medical people's roles and I think…there seems to be like a *clash* sometimes and if everybody can figure out what their role is.

> …there are people who feel that they can *control* every situation in their life outside of this place and they have a very hard time giving up even the smallest amount of *control* when then they are here on this unit. And I agree, yes, if it is your baby, [and] you're the parent, of course you are going to have your own feelings about things, your own

> invested interest in things but when [my child] is sitting in the dentist chair and …I don't have the education about certain things, I am not telling my dentist how to drill my [child's]…teeth…I find that there are certain scenarios that have been happening lately, where, it has gone beyond what. I guess this is where we have to sit down: Family-Centred Care, what does it mean?...What are the roles? And what is the set point where parents have the ultimate say in decisions?

Lack of Essential Resources

The study participants, who experienced challenges of practicing family-centred care, realized that a firm understanding of the approach was required to strive toward supportive partnerships and recognition of the parents' care-giving role. Embracing diversity in families and adapting nursing practice to respond to the needs of the families was necessary to successfully incorporate this approach in the NICU. The participants struggled with how to accomplish this goal. Factors such as lack of education, collaborative support and workload constraints influenced their ability to consistently provide a family-centred care NICU environment.

Insufficient Education

The study participants perceived that there was a lack of relevant education in relation to family-centred care knowledge and subsequently applying the concept into clinical practice was limited. Insufficient education led to the perception that there was a diminished commitment of other practicing NICU health care professionals, in addition to the nursing staff. Primarily, a lack of empathizing with the families, and understanding the needs of the families resulted in knowledge deficits concerning the principle components of family-centred care. Furthermore, methods required to actualize those components into

practice were limited. The participants explained their "need to be educated" and their "need to educate the vast amount of people in family-centred care".

> ...you will go up to a nurse and you'll say: What do you think about family-centred care? And they think that we are already doing it and I am like O.K. (laugh). Me knowing what I know, I know we are not a family-centred care unit totally. We probably are more progressive than a lot of hospitals are because we have NIDCAP started here...
>
> It's the *understanding* of what a family-centred care unit means too...I think the education needs to get out about what does that mean, it's a really big...thing. A global concept and for you to say [in] your information brochures that we are a family-centred care unit...[we then must be] able to follow-up with family-centred care [practice] and support that. [It] is important.
>
> [In asking families]...what is your plan for today type of thing...The [families] don't get that a lot. They get *ignored*; you're in the way type of thing. It is just sitting down in a chair beside them and just spending five minutes talking to them...

Whether intentional or not, sharing information was important but not consistently practiced. The participants identified that an inordinate amount of responsibility for practicing family-centred care fell on the more experienced, senior nursing staff. The study participants perceived that less experienced staff nurses were unable to counsel parents and families in critical situations, and therefore were less able to support family-centred care.

> ...when you are new, you are more focused on the tasks versus the rest...You have to be, because that's what they are in the process of learning and then the icing on the cake is learning basically how to build a rapport [with the family]...
>
> ...I was [precepting] a new person. We had a *difficult* family...and the question came up about a third course of Indomethacin, PDA ligation etc, etc. This new girl [did not]...have...one *ounce* of background knowledge to counsel this mother who is a registered nurse, who is very *demanding* of answers and you know what? ...I was there with the experience to counsel [the mother] through that day and I'm telling you, that [new] nurse had enough on her hands monitoring the pumps,

> repositioning the child, suctioning the child, and she said to me at the end of the day, "I don't know how the heck you did that"…I explained to her, "I didn't just walk in here yesterday…What I discussed with that mother came from years of experience of working with critically ill children". So, I think in the beginning they have to focus on their little tasks.

Although the study participants all believed their practice most often reflected the family-centred care principles, they recognized that at times, their practice suggested otherwise. For some of the study participants, the needs of the parents were less valued and thus infrequently offered by the staff, especially in instances where families were considered *difficult* or *demanding*. Furthermore, the participants identified the importance of mutual respect and trust in enabling them to willingly support the implementation of family-centred care. Disrespectful interactions contributed to the perceived alienation of both parties, thus creating a hostile environment for both the families and the interdisciplinary staff. Examples of parental involvement that harmed active participation were mentioned:

> …a father felt it was his position to tell the [staff] how to perform [medical procedures on his child]…It got to the point where nobody even wanted to look after that family…[nobody] wanted to go into the room if the father was there…It made it very uncomfortable for the staff…and I actually specifically heard…[staff] who were not really wanting to be involved anymore. So at what point do we…not *allow* this to happen so that it [does not] become *abuse* to the staff?…I don't want to *dread* coming in to work because one man is making people feel that uncomfortable and awkward…Those are the cases [that] we need to look at [and decide] what are we going to do about those things…

> ...parents have gotten utterly *rude* and abrasive to one of the nurses on the unit who has been here for 20 some years, and [the mother] told her not to *patronize* her because she's the mother. Just because the nurse said, after [the infant had a] full day of x-rays, LPs, [etcetera] 'I think the baby really needs a break right now', the mother turned

> around and said don't you dare *patronize* me. Now what was that nurse supposed to say to *that*?
>
> ...there are two sides to [every story]...but there are times when there are huge issues about resentment towards families...that ultimately hinders [family-centred care]
>
> no one wants to take those assignments if you are going to be treated like you are the *worst* nurse ever and you feel like *crap* by the end of the shift, it is just not a fun assignment, not that work has to be fun but you just don't feel good about yourself at the end of the day. You feel like you have not accomplished anything.

Even though the negative attitudes toward families were felt to be a problem among all members of the health care team, the study participants assumed that nurses' efforts to facilitate family involvement and initiate accepting attitudes toward families were hampered by practice misperceptions regarding implementation of family-centred care. They indicated a need for multidisciplinary educational curricula and supportive tools to enable incorporation of family-focused knowledge.

Collaborative Support

The study participants identified the importance of widespread managerial and multidisciplinary support for influencing their family-centred practice. Overwhelmingly, the nurses echoed each other in describing experiences that suggested a perceived lack of commitment from other health care professionals. Practicing family-centred care was described as "not a priority".

> I don't think that family-centred care is supported that well. So right there, that is the mentality of what people think about family-centred care, it is not a priority. It's not supported by management [and] staff. That is what I find here. It is not priority.

Additionally the participants perceived the other health care disciplines claiming to be incorporating the philosophy into practice were not fully practicing the family-centred care components. The physicians and the nurse managers were perceived to be practicing "superficially", in keeping with a supervisory role in the NICU. They were recognized as leaders by position, not by practical wisdom. Furthermore, the "physicians, unit managers and other disciplines" were identified as ineffective role models because these professionals were not seen as having practical experience.

> ...it still comes down to it's easy to *walk by* and say something for five to ten minutes than to be there for the other 11 hours and 55 minutes of your shift and actually have to carry all this stuff out. That's why I think the nurses need more support and understanding of what they are going through at the bedside having to incorporate all the family-centred care ideas into our daily practice. Because *we* ultimately are the ones that are doing it but *we* are also the ones that look like *we* aren't the ones that are on board like the rest of them.

Although the NICU's organizational policies and programs were seen as promoting the needs of the families and encouraging maximum involvement of families, the nurse participants explained their feelings of adversity with respect to ensuring appropriate environments for themselves. Furthermore, in comparing their nursing role in providing family-centred care with the roles of other multidisciplinary team members, it was recognized that there was a failure to meet the needs of the practicing staff nurse.

> ...I mean family-centred care needs support of all the other disciplines...and by definition, it's not just the bedside nurse who is offering family-centred care; it's medical disciplines, it's everybody from the unit clerks, to the bedside nurse, to the doctors, to the social workers, to pastoral care, to the occupational therapist, to the respiratory technicians...I think it should involve all of them and we should all be supporting each other which I think the nurses do, the

> nurses are supporting each other because, as a rule, it just doesn't happen that the [other team members]…are supporting us when we need them.
>
> …this is what I'm saying about other disciplines who walk by the bedside and have their five to ten minute interaction being…not understanding of what the bedside nurse is going through.
>
> …I believe that if you now included the social worker, the physician, the unit manager and all these other disciplines in this room right now, they'd probably feel like "What do you mean? We do family-centred care and it's easy for them to say that they are really on board and…they probably look like they're more on board than the rest of us because we're saying these negative things…

Some of the study participants felt the negative comments made by other health care professionals negated their desire to build collaborative relationships with parents. There was an overwhelming frustration directed toward the nurse managers. The following quotations describe this feeling:

> …there was never support. Anytime anybody went to the manager about that family, it was [disregarded]. The big issues that went on and one of their responses was 'I'm not rocking the boat right now because [the mother] is having a good week'…The *nurses* are not having a good week. So, *had it* been [dealt with] when all those things were going on, I don't think it would have gotten to the point that it did. We're talking over months here; we're not talking over weeks. Something needs to change to support the people who are doing the looking after [the difficult families]…
>
> …How about just hearing 'I know this is a difficult family to look after'… But [instead] it's 'Well it's your job'… 'Be more professional'. Two totally different ways of supporting [us]. How does this affect family-centred care at such a critical time when we're trying to incorporate it?

One nurse experienced the "lack of support" as having a spiralling effect because the harmful comments contributed to an increasingly negative environmental mood. In turn, motivation to foster positive practice was diminished and job satisfaction was strained.

> The attitude right now with the staff, it's going more and more in the direction that it has left such a bad taste in people's mouths that even the people who believe in the philosophy of NIDCAP / family-centred care / primary nursing, whatever words you want to use, as soon as you throw those words out at people right now, people get their *backs up* and start *running* in the opposite direction. And it's *negative, negative, negative talk, talk, talk* because people are just right now; it's got such a *negative* connotation because of everything. And it's *lack* of support for the nurses.

> I have heard …other disciplines say 'Oh, you *really* should do this and this and this, you know' without talking to the bedside nurse about it. What she's experienced that day with the family, with the baby's condition, etcetera. It's like why do we have such a *low role* sometimes on the totem pole …We're the ones…that are here 24/7…and that's where I say there is the ideal and then there is what is happening [in reality]. When you are the bedside nurse dealing with all that, by the end of the day, it can really suck and that's why people have their *backs up*… I think right now, we've hit the point where people don't even want to talk about [family-centred care].

Additionally, at times, the NICU practice environment was felt to be non-supportive. Participants felt that there was disrespect from the parents and other health care providers as well as among the nursing staff. This created added strain within the unit as the participants described feelings of intimidation and "being attacked". Although the nurses recognized "their own" as informally supporting each other, the hurtful comments countered the supportive ones. Instances where nurses were perceived to be at the breaking point were described: "nurses yelling at each other at 6 a.m., at the top of their voices, slamming down charts…and the [management is] going to say 'there is not a *problem'...Morale* is in the *toilet*". Dialogue between two participants further explicates this phenomenon:

> …[we] have to face the fact [that] the only support we get is what we give each other…and this is an example from the other night where a 20-year veteran [nurse] was made to cry, on the verge of tears because of the way a mother treated her, and it was the nurses on the night shift

> giving her hugs, telling her not to worry about it, you're an awesome nurse. But why are we getting to this point?

Furthermore, the study participants acknowledged perceived feelings of personal devaluation, especially when their expertise in the clinical care setting was disregarded either by the team or by the families. The comments made were perceived as "*condescending*" and "*critical*" and these experiences were upsetting to the group and stimulated further discussion.

> I know it happens on a daily basis. It's like when you're giving report. You might as well say the most *outrageous* things because really *nobody's* listening to you. When you are trying to say something [during rounds] and you've been at that bedside for, let's say, 3 straight 12-hour shifts and you've noticed something, it's like 'how would you possibly know, you're just the bedside nurse' and it's happening everyday, at every bedside…
>
> …Somehow there has got to be some message sent across here [to the families] that the *nurses* do have some knowledge on this unit and some experience and are able to make…decisions without [other health care staff]…going against what a *nurse* says on rounds the next day, or making *ignorant* comments…to the nurse…or *criticizing* what a nurse is doing…

The participants were additionally concerned with a hierarchical division within the NICU that further contributed to their own low esteem. The participating nurses believed they practiced proficiently in this intense, medically complex, acute care area; however their nursing practice was questioned by other health care disciplines and was misunderstood by parents and families. As one participant stated, "I think some parent's view the physician as being in charge…The [physicians] are the ones with all the knowledge." The perceived social norm for respect for the doctor was felt to interfere with the participant's practice knowledge and expertise.

> ...the father's words were to the nurse was 'that's why we come around on rounds so we can listen to what the doctor says because you nurses do not know what you are talking about anyway'.

> ...*I* had physician tell a family...[when] the infant needed to go back on [continuous positive airway pressure] CPAP...just come see a [respiratory therapist] RT or the doctor. Skip the whole nurse phase and go right to the doctor...

> I'm feeling like nobody respects what I have to say around here...Family-centred care is our goal but so is the well being and the mental welfare of ourselves [the staff nurses]...

The intensity of the discouraging family-centred care experiences varied among the study participants. Discussing the endless layering of these stories created tremendous frustration in the group; however they were keenly attentive to each other's stories and collectively generated feelings of support for each other.

Workload Constraints

Family-centred care was perceived to increase the overwhelming workload experienced by the study participants. The current staff shortage and time constraints were both perceived as having a negative impact in providing a family-focused environment. Furthermore, the participants recognized these limitations in their attempts to engage in the collaborative relationships with families.

> It is the busyness of your day, how organized you are with your care. If you have the extra minutes to spend with families to talk to them, teach them things, help them hold their baby, that sort of thing. What we think is important. Busy place, you know. If you are getting admissions in your pod then that is not a good time to be doing that either. It all depends on what is going on [in your pod or on the unit].

> Depends how heavy your assignment is. If you are really busy, you don't have the time if you have got 3 patients. You don't have the

> time to [spend] with [all your] families so it depends how heavy your assignment is. The kind of shift you're working. If you are working nights all the time, you don't see the family.

Besides staff shortage and time constraints, a further challenge to nurses was said to be that the substantiation of competent professionalism placed a considerable amount of importance on scientific credibility rather than the artistic nature of caring.

> …it takes a lot of extra work [to incorporate the family]…let's face it, it's a lot easier when you have the assignment where there are no parents around…People say it, …it's easy to walk in and just do tasks…
>
> …It does take a lot of extra work to not only incorporate the family but also the other nurse you've got to train to do the job…
>
> I think we have more patients then we used to have and there's more twins, there's more triplets that makes it busier, you know when I first started in the NICU, the babies were really, really sick but we didn't have what we have now to look after them, you know what I mean, so they do better now but they are more chronic, you got your babies that are here for a longer period of time because we are saving more babies at an earlier gestation which means that they have to be here a lot longer and the families are more involved and that makes it busier too because back then the families weren't really welcome to be involved so, it was just 'do your work'.

In addition, the nursing assignments were a reflection of the medical acuity of the infant, not taking into consideration the family needs and dynamics. Unstable infants requiring substantial nursing attention would potentially have a 1:1 patient-nurse ratio whereas less acute infants prior to discharge would have a 3:1 patient-nurse ratio. The study participants identified examples where the value of "sitting down and talking to the families" or "teaching families" was put on hold until they could get their necessary tasks done, thus potentially leaving families in need of further supportive teaching.

> ...we always look at the acuity of the patient...Medical status and let's say this baby's on CPAP, this baby's on a continuous drip, we look at those factors. I think when making assignments it's not always looked at, "Oh this family has got X, Y and Z", this assignment has got three sets of parents at the bedside all the time and this assignment in the same pod has got three sets of parents that aren't coming around or maybe there's one mom that's coming in quickly to drop off milk. The assignments with all the visitors and the parents are the busiest assignments and we view busy as acuity of the medical things...Sometimes when the parents are here all day, they go for supper, they're back in the evening, they want to be involved in the bath, the weight, the 'this', the 'that', the Mom gets up three times a night, they're phoning all the time, those are the busy assignments. Once you have your physical tasks done in a day, and you're the type of nurse that feels comfortable in those things, that's not the busyness anymore. The busyness is dealing with all the other stuff and I don't think that is taken into consideration when making the assignments.

Workload constraints were not conducive for providing consistent primary care nursing. The study participants implicitly recognized the strain of trying to accommodate staffing for a 65-bed unit while fostering primary nursing. As one participant describes, "primary nursing is hard to do on this unit...when you have 350 staff members working". Felt to be integral in primary care practice was consistency, and the participants often spoke of experiences where the consistency and continuity of care were inhibited by staffing constraints.

> ...It's the way staffing is set-up...it depends on how eager you are to do your primary care so...if you really, really want to push to have your assignment, you really have got to *push* to have your assignment back...

> ...it is the way staffing is set up. So sometimes, the [people making assignments] don't make provisions so that you have your same assignment back. Either they have you doing something else or ...or the same person had the baby yesterday and wants the baby back today so, consistency... [in the fact that] you don't get to do your primary care nursing. So there are many things that don't support it in a way.

> ...The problem is...historically, our primary care teams...have a maximum [of] 4 and if you are lucky 5 people [most] of them have 2

> or 3 nurses signed up…If you look at whether these people are full-time, part-time, what shifts they happen to [work], …days off, if it's an 8-hour versus a 12-hour person, etcetera, sometimes primary care nurses actually only look after…their primary [infants] 1 or 2 shifts in a week depending on assignments.

In addition to the continual challenges of staffing requirements and limited resource allocation, experiences of practicing primary care were perceived as creating some level of emotional turmoil for the nurses. For the study participants, volunteering on primary care teams generated feelings of physical and emotional fatigue. Each nurse revealed that developing a social bond with the infants and families was "draining" and the desirability of having the same assignment for months on end was "unappealing" for some of the participants. As one nurse revealed:

> …besides staffing issues [and] desirability, I will tell you now if I have to come every day to work for six months and look after the same patient, I will *not* be happy here…it's tough getting that involved with people during these very fragile times in their lives and I know it's our job…but what I can bring to different families on different assignments versus feeling drained at the end of two, four or six months with people, well I don't even think I'd be functioning at my best if I had to be honest with you. I think I can bring a lot to families but I don't think I need to bring the same thing everyday to the same family…I don't think I'd be at my optimal by the end of it because I would be very *drained*…There is a certain limit and you need to recognize that in yourself…

Clearly, the lack of essential resources was a central phenomenon in influencing the participants' family-centred practice experiences. These experiences also impacted their inherent desire for consistency, in so much as participants' perceived contradictory practice and inconsistent communication to adversely affect family-centred care. This further divided the collaborative partnerships of families and health care professionals.

Inconsistency

Although the study participants recognized consistency of care and accordant information precipitated the successful implementation of family-centred care, inconsistency in following policy and conflicting nursing practice was thought to hinder the practice. Furthermore, the quality of information provided by the health care professional to the parents and families influenced the ability to provide family-centred care in the NICU.

Following Policy

The NICU has practice standards and policy guidelines that assist in maintaining consistency in practice. Adhering to the accepted neonatal recommendations, which are viewed as the "standard of care", improve the "quality of care" for infants and families and maintain good patient care continuity. The written policies, put in place by the Northern Alberta Neonatal Intensive Care Program, are intended to provide direction for the provision of optimal patient care. The study participants recognized "following consistent policy" was fundamental in the effective implementation of family-centred care. Excessive variance in complying with the documented policies meant added stress for co-workers and families. Additionally, the participants understood that the families trusted knowledgeable proficient health care providers. Any perceived distrust by the NICU parents and families was largely attributed to organizational confusion. Furthermore, the participants thought disrespecting NICU policy created a somewhat hostile working environment.

Adhering to the current visiting policy was thought to be a challenge by all study participants. Thus it provided the most discussion. As one nurse stated "I really think our visiting policy needs to be reviewed and then needs to be consistent from every nurse". Other participants provided their insights:

> ...There is a difference between opinion like...you should breastfeed in this position and...and *then* there is policy....There [are] a lot of nurses who are very lenient on the visitors and there is...20 people at the bedside. [The] next nurse comes in and is very adamant that you are only *allowed* [three] people at the bedside, and then the family gets all confused. Or they will see another bedside has 15 visitors at it and there is *no* consistency at all...A lot of nurses [say] 'well it's quiet in here, sure you can have five more visitors' and then it just gets more *frustrating* when the family your caring for wants more visitors. There's *no* consistency at all.

> The visiting policy...*Nobody* follows it...I may say you can have three people at the bedside...and all of a sudden there are 12 people. If you want confidentiality, it's not going to happen when you've got all these other people sitting at the bedside...

Further concern was the perception of the benevolent and malevolent nurse. One study participant felt it was unprofessional to undermine the integrity of nursing co-workers. It was understood that in the attempt to create collaborative relationships with families, the perceived *bad guys* adversely affected the development of these partnerships.

> ...One problem [with the visiting policy] is it's hard to have more than a certain number at the bedside. But the [bigger] problem is that there is *no* consistency in this visiting policy and people do whatever they feel like doing, and the nurses will allow five people at the bedside and you come on the 7 o'clock shift change and there's five people standing there. Now are you going to be the *mean nurse* and say 'I'm sorry, two of you need to leave"? You look like the bad person for the next 12 hours...If people were more consistent with the visiting policy then some of us wouldn't have to look like the *good guys* and some of us wouldn't have to look like the *bad guys*.

> Just like Grandma reading a chart…that's inappropriate and I say 'I'm sorry, the parents can review the chart…but you cannot be reading the chart'…The other nurse…whose actual assignment it was, didn't see that [as] a problem. Now, why does one nurse in the pod need to look like the bad person? We have rules for a reason and I think we all need to get on the same page here. Personally in the end, I think it does the parents a favour if we all follow consistent rules. This *wishy-washy* one person do it one way and [another do it that way does not help the families]…

Nursing Practice

Given the effort involved in implementing family-centred care practice in the NICU, the study participants reported that consistency in nursing practice remained a struggle in a unit that employs a large number of nursing staff. Between the full-time, part-time and casual nursing staff, there are over 180 employed nurses in the NICU at the RAH. Furthermore, at any given time, there is a constant influx and efflux of staff nurses. This was thought to create a continuum of learning and subsequent teaching by the veteran nurses.

There was a division between the "junior nurses" who were felt to not have the "maturity to deal' with all facets of NICU care versus the "experienced staff" that had practice "expertise". The newer staff were thought to not follow consistent practice guidelines because they were still in novice positions and were "basically [still] learning how to deal" with families. Some study participants were cognizant of this segregation and thought it added to an already strained NICU environment.

> …[junior nurses] are sweet and nice, young and unscathed and probably more tolerant because they allow parents to do certain things because they don't have the experience…[They are less able to] counsel the parents through difficult times or even give appropriate information….

> ...[new orientees] have so many other things on their mind and they are trying to be nice to the families...They are going to do what the families want, especially the more controlling [families]...The newer staff are going to be more apt to do what the parents say...
>
> ...I'm...listening to the new nurse X tell Grandma all the medical information about...[the infant and I'm *appalled*...Do I]...tell her...you're really not supposed to do that? Or do I just keep my mouth shut and just smile because...tomorrow I'm going to [be caring for that family] and I'm going to have to say 'No I'm not going to tell you all that information' and have that Grandma freak out at me and get all *snarcky* with me?...

The perceived inexperience was closely connected to newer staff not providing consistent nursing practice. Thus, it was felt that parents and families were less trusting of the nurses.

> ...I have seen parents then go against what a 20 year veteran will say because that's not what...*Suzie Q* said the shift before. *Suzie Q* has been here for only *nine* months. It starts to become...a *problem*...We are all coming from different backgrounds...with different experience and there is inconsistent things that happen. This is one point that when people think that it is ok if I do something this way or I'll just sway and do it that way, I think that is one of the big problems on this unit. Swaying from the way we should be doing things or changing rules. I think in the end it is ultimately detrimental to family-centred care because it makes the parents untrusting of ...staff. 'The last nurse said I could. The last nurse did it this way'...

The participants were also concerned with how many opinions were given to parents and families. Opinions were perceived to provide parents with ambiguous information that did not assist the families in making decisions.

> ...Is it fair for parents to...have all these different [health care practitioners'] opinions?...I think that's why we need to have more consistency around here because you are going to have a million different opinions and imagine how frustrating it would be as a parent to hear all these different opinions...
>
> ...When I approach a bedside...I always say 'that person might have said this, however, you are going to run across several other nursing

> staff who will be caring for your infant and they will all have their own opinions'...

Primary care. All the study participants acknowledged the relationship between primary care nursing and family-centred care. Primary care nursing offered the families, by definition, a family-centred NICU experience. As one nurse stated "family-centred care requires primary care teams". Despite the participants desire to facilitate a positive NICU experience for parents and families, some of the participants struggled with the feasibility of implementing primary care teams for all infants and families. There was a discrepancy between their perception of what constituted a family-focused environment and the practicality of primary care practice.

> ...it's not realistic to have a primary care team for every baby...I think it's ideal...but it's not realistic...it's not realistic in the sense of it is so draining emotionally, physically...you'll get a lot of burnt out people...and you won't have the staff...

The participants' all spoke of their primary care experiences as being both physically and psychologically draining. Furthermore, the participants identified that in order to foster full nursing participation, the primary care concept needed to be defined and new guidelines needed to be developed.

> ...the problem on this unit is that there is no [direction regarding] what is primary care. People will do primary care on level 2 where as this baby may have been here for already 4 months. Do you know what has gone on for that time? I am...a firm believer if you are going to do primary care; it's got [to] start from the intensive care side...

> I think they need to set guidelines out to start off because it is not an automatic thing that every baby gets primary care nursing. I think we are all supposed to supply family-centred care to every single baby that is born [and] in this unit...The concept of family care nursing should always be there, no matter if you have a primary care team or

> not, but I think the best way to do family-centred care is to have a primary care team.

In discussion, the study participants acknowledged inconsistencies with how primary care teams are set up on the unit. The process of arranging teams in the NICU is primarily under the direction of the unit managers. Parents will also take an active approach in soliciting a consistent nursing team once they become aware of the primary care concept. One participant accurately describes the process of team formation.

> Management usually sees a family [who] is really overly stressed and [decides] they need to have a primary care team or the baby is particular so…they need a certain way at looking after them that consistency can provide. [A manager will] approach the family or sometimes the family will approach the nurse and say…'we want the same nurses looking after our baby all the time and not [to] be changed all the time'…From there, the [manager] will put out a VAX [email] and they'll ask for nurses to volunteer to be on the primary care team. That is the way it is supposed to be done but it is usually done under the sly where the parents are soliciting the primary care from the nurse they like that certain day or whatever and then that becomes their primary care team.

Although primary care nursing was thought to be supportive for providing family-centred care, some participants questioned how primary care teams were designed and implemented. The participants recognized that not all long-term infants received primary care nursing. Furthermore, infants perceived as needing consistency and continuity of care were not automatically assigned a primary care team. As a result, the current guidelines for selection of infants and families were likened to "a squeaky wheel".

> …primary care teams on this unit, which is supposedly a big part of family- centred care, seem to get setup for certain types of children and there are children on our unit right now, long term children, who are of a certain class, parents who don't come [in to visit]…and there

> hasn't been one email sent out whether anyone wants to be on these primary care teams. The primary care teams tend to get setup on this unit for the upper class, Caucasian, *demanding*, educated parents. So who are we setting up primary care teams for? Yes I do believe that part of it is for the parents because you're there for support for the parents and stuff, but, I mean *ultimately*, my job is to come and look after the *baby*. And I find it amazing that we do not always pick out the babies that need the primary care nurse, the *babies* themselves. We're looking at parents needing consistent care here when we're choosing [primary care teams]…Some of those *babies* need consistent care as well.

For some participants, the perception of soliciting primary care teams for the more "*demanding*" or "*difficult*" families lessened the participants' desirability for volunteering on primary care teams. As one participant explains "[creating primary care teams begins] usually…after the baby has been here a few weeks…when the [parents] are just really stressed". Hence, this "turns the nurses right off and they don't want to be on the primary care team because [it takes] so much extra work…It sets people off from doing primary care nursing".

Thought to impede the primary care initiative was having nurses with limited experience practicing on primary care teams. Having novice nurses on primary care teams was identified as not in the best interest of the infant or the practicing inexperienced nurse. The participants understood the need to develop knowledge and practice experience during the first two years of NICU nursing.

> Another barrier too, is the people who think they should be doing primary care nursing [that] maybe shouldn't be doing primary care nursing. They don't have enough [experience], especially [with] the really sick babies. They don't have enough skill [and] understanding. The really [inexperienced] nurses,…it's not really fair to say, but it is fair to say they don't have enough experience in dealing with families and what they go through and [those nurses] just need more experience period. I find that those [nurses] are the people who are signing up for primary care nursing and primary care nursing is…not thought of family-centred care yet, not here. Sometimes I think they [nurses] are

> just there to look after the baby, they really don't have to deal with the family but that is the huge part of primary care nursing; helping the families and I don't think they realize that sometimes. It turns them right off from doing primary care nursing and you get stressed and you get tired. It's emotionally tiring.
>
> I really think at least two years experience, and they have to be that kind of person that will really give it their all and not do it just because they want that same assignment or because they want to be on level 3 all the time or they want to be on level two all the time, because that plays a factor in it too…They do it for the wrong reasons, I think and that is not helping the family at all.

Primary care nursing was also hampered by the provision of nursing assignments. Although the primary care concept is associated with providing consistent nursing coverage, this was not seen as feasible in the everyday operation of the NICU. As previously discussed, staffing constraints are a continual phenomenon experienced by the organization. Providing full-time primary care teams for a majority of the NICU infants was equally strained; however the participants did not see this as a hindrance to the in practice of primary care. For some of the participants being on a primary care team meant supporting the infant and family even during times where direct patient care was not possible.

> It is the *understanding* that you're there to support the family which doesn't necessarily mean that you have to have that patient every day. You're there to support that family. Go talk to them on your shift. You're still supporting that family.
>
> …primary care…does not mean you are going to get the same nurse everyday. It is too hard…the concept of family care nursing should always be there, no matter if you have a primary care team or not…

Many factors influenced the study participants' perceptions of fully incorporating family-centred care into their everyday NICU practice experiences.

Fostering this environment was inhibited by perceived barriers and limitations. Although the participants believed that providing a family-focused environment for parents and families was optimal, the evidence suggests that the participants' practices failed to reflect their commitment to the approach. As a consequence, their behaviour and attitude explicitly influenced their care of the parent and family.

Summary

In this chapter, the findings of this phenomenological study have been presented. The participants family-centred practice experiences have been explored with respect to what the concept meant in their context of practice and their understanding of how family-centred care is applied in the NICU. The participants understanding of dimensions of practice barriers were presented.

The final chapter will focus on reviewing the findings, discussing the strengths and limitations of the study as well as examine additional related research arising from the study. Furthermore, I will explore recommendations to aid in facilitating a family-centred approach to care in relation to implications for nursing practice. These recommendations will be a compilation of suggestions put forth by both the study participants as well as myself following review of related family-centred research.

CHAPTER V: DISCUSSION

The purpose of this study was to explore nurses' experiences in practicing family-centred care in the NICU environment. The research questions guided the discussion on nurses' perceptions and reported practices in implementing this approach to NICU practice. In this chapter, the research findings are interpreted in relation to my own experiences as well as to comparisons with existing studies on family-centred care. Because of the limited literature available pertaining to family-centred care practice in the NICU, research relating to family-centred care in the acute care and paediatric populations is included in the review. Following this, implications and recommendations for nursing practice are discussed. The strengths and limitations of the study are identified and I suggest additional research directions that arise from this study.

Interpretation of the Findings

In this research, an interpretive phenomenological design was chosen for this qualitative study. This method provided an approach well suited to exploring the nature of the neonatal nurse's experience in practicing family-centred care. For the participants, this study provided the opportunity to uncover what was significant in their everyday nursing practice as they incorporate this approach in the NICU. In the previous chapter, the participants' narratives offered an enriched dialogical description of their family-focused experiences. "These narrations were the vehicles to access understandings" (Conroy, 2003, p.12) to critically reflect on what the study participants' said. Fundamental in the process of analyzing the narrative text is exploring the mood which is embedded in the

text (Conroy & Dobson, 2005). The mood directs social interaction and is subtly entwined in the interpretive process of understanding the expressed narrative.

> Mood is a particular feeling or affective state of being engaged in and with the world…[providing] a gateway into understanding how a person is faring from an existential standpoint. It discloses what they value as authentic or unauthentic" (Conroy & Dobson, p.977).

In reviewing all the study recordings, including the verbal, the non-verbal and written notes, the emergence of significant themes was evident. Throughout the interpretive process, I was attuned not only to the narrative text of the participants, but also to the atmosphere in which the interviews unfolded and my own preconceptions of the participants' experiences. As the investigator in this research, I was consciously aware and acknowledge the influence in which the narrative text was interpreted. Throughout the research, my personal involvement related to enhancing family-centred neonatal nursing care and while I sought to make explicit the values and assumptions of the nurses, I brought my own interpretation to the research (Benner, 1994; Conroy, 2003). Although I have an extensive NICU nursing background, during the interpretive process, the experiences of the participants became subject to scrutiny and I had to open myself to the hermeneutical spiral of interpretation. As described by Conroy, p. 14:

> Within the hermeneutical spiral of interpretation, both researcher and participant build on their background interpretation as each reflects and interprets what is happening within and across the narrative and interview sessions. The hermeneutical ripple effect of the spiral is dynamic, impinges on others' interpretations, and overtime, changes the understandings of all. Ongoing interaction engenders reflection and active dialogue within the narrative sessions, the research process, and continual re-interpretation of the world. It includes sharing

> personal values, beliefs and assumptions, and reflections between participants and researcher.

To assist in maintaining an orientation to the participants' lived experiences, the activities of journaling and validating transcripts were carried out. My initial interpretations were audited and discussed and with a secondary reader, (Dr. Conroy) followed by verifying the corresponding interpretation with the study participants.

In abstracting the themes from the participants' narratives, I analysed their experiences with respect to how those experiences existed in their world. As cited in Conroy and Dobson (2005), Heidegger's philosophy of being-in-the-world describes ways people exist in the world: authentically, inauthentically and undifferentiated. These form one foundation for interpretative phenomenology.

> A person would be existing in an authentic mode if he or she were living up to what he or she felt to be significant, even if it were at odds with what is socially acceptable…Put differently,…the authentic person assumes control of situations with resoluteness and is dedicated to his or her goals…An inauthentic [person] would be assumed by someone who actively takes on the public way of doing something, even though that person does not value that way of existing…In this inauthentic mode, we are not our own person…The undifferentiated mode is one in which we exist unreflectively most of the time (Conroy & Dobson, 2005, p. 98).

Positive and Negative Family-Centred Care Experiences

Analysis of the study participants' narratives reflected both positive and negative perceptions of family-centred practice encounters. Although the nurses understood the family-centered philosophy to mean advocacy, support and collective collaboration between families and health care providers, key findings

indicated there was a discrepancy between their knowledge of the philosophy and their everyday nursing practice.

I observed that the study participants' positive experiences centred on support from colleagues, clear communication and encountering positive family interactions. These events reflected expressions of mood such as authentic, honourable pride and self-esteem for the study participants. For instance, participants verbalized; "[A] part that is really good for me is…I get to be really involved" or "they also respected what I would say".

A struggle with nursing identity and professional attitude, a lack of organization and bureaucratic support and negative family interactions brought about feelings of anger, powerlessness, frustration and ambivalence, which consequently contributed to perceived unfavourable family-centred care experiences. Key findings from this study reveal the study participants' positive and negative experiences influenced authentic family-centred nursing practice in the NICU.

Support versus Lack of Support

The study participants placed emphasis on the support they received from each other as nurses practicing in the NICU. This support gave reassurance of their self-worth as competent practitioners in a highly specialized NICU environment in addition to feelings of caring and esteem. Reciprocal emotional support and comfort offered by nursing co-workers during negative work related experiences was vital in contributing to the well-being of the practicing bedside nurse. Furthermore, this supportive care characterized by trust and respect was an

integral part of their role as bedside nurses and was felt to be central in their ability to form interpersonal relationships with NICU parents and families in the practice of family-centred care. Consistent with the findings of others (Brown & Ritchie, 1990; Binnie & Titchen, 1999; MacKean, Thurston & Scott, 2005; Rushton, 1990; Thokgamo, 2003), shared support influenced the ability to provide family-centred practice.

Although the study participants believed a family-focused service lead to benefits for both families and health care providers, the participants also acknowledged negative experiences resulting from this practice approach. Negative perceptions were associated with a non-supportive workplace culture which not only affected the mood of the environment but also pushed the nurses' interest toward inauthentic practice of the family-centred care tenets. Impeding the participants' practice was a perceived lack of multidisciplinary support, various workload constraints and inconsistency in adherence to policy. Among the group, each participant experienced varying degrees of these impediments.

Recognized as being a difficulty was building relationships with parents and families during times when their nursing expertise and knowledge were perceived to be undervalued in the practice setting. Additionally, workplace tension was reported when members of the multidisciplinary team conveyed demands on the nursing staff without providing appropriate support or guidance. The "derogatory comments like 'that's your job [because] we do family-centred care'[or] 'don't have fun at work' " were identified as contributing to a negative work environment and consequently generated feelings of resentment rendering

nurses incapacitated to be able to practice authentically. Nursing teamwork suffered; incorporating family-centred care was described as having a "negative connotation" producing "negative reactions" to practice. The accompanying moods of anger and frustration were reflected in one participant's comment stating, "You really can not provide family-centred care in *that* kind of environment".

Wilson, McCormack and Ives (2005) studied workplace culture and nursing practice in a special care nursery. Although their primary aim was to understand the values and beliefs of nursing personnel in the attempt to change workplace culture, Wilson et al. described key findings linking good leadership with generating teamwork and a positive work environment. Drach-Zahavy (2004) examined the impact of primary nursing and management support on the staff nurses' appraisal of practice performance. Although that quantitative study was conducted with nurses serving an adult population, the findings suggested "primary nursing [by itself] did not have a direct impact on nurses' performance. For nurses practicing a high degree of primary nursing, their performance level was significantly higher when supervisor support was [also] high" (Drach-Zahavy, p.13). Even though these results indicate managerial support improves primary nursing performance, other studies have linked primary care nursing with increased job satisfaction (Sellick et al., 2003; Thokgamo, 2003) which could also be attributed to improved nursing practice. The dialogue between the participants in my study reflected a consensual need for and desire to seek positive support

from all members of the multidisciplinary team, including the managerial nursing staff.

Frustration spiralled when tension mounted within the NICU environment. The participating nurses acknowledged feeling that they were pushed to their limit in their ability to cope with the emotional and physical stresses of working in an intensive care unit. The participants spoke of a loss of morale and felt overwhelmed as they continued to take on more nursing duties as they cared for infants with complex health needs. Often the experienced nursing staff were "pulled to do charge" adding to their stress level. One participant who experienced being continually pulled away from her role as a primary care nurse to complete other nursing roles within the organization commented on how her "priorities were pushed to the bottom again". Another participant gave a different reflection of taking on charge duty. She explained "sometimes being in charge and having to deal with all the family issues on top of staffing, etcetera…there are days when some of these things that would help family-centred care become your nemesis by the end of the day".

Comparison of these two reflections confirms how important the interpretive process becomes in understanding the meaning of what is being said. For one participant her emotional stress was a reflection of not being able to be "with" the NICU infants and families whereas another participant identified her tension as having to deal with multiple family issues within both a nursing and managerial context. All of the study participants complete charge duty on a regular basis; because of their seniority they must act as management substitutes

on extended evening and night shifts. In both cases, a mood of frustration with the loaded work assignments highlighted a sense of powerlessness to act as authentically desired.

Fuelling the negative mood, other limitations identified as not conducive to facilitating family-centred practice were the current staff shortage and time constraints. A challenge for NICU nurses exists in a work environment where competent professionalism is perceived as being related to proving scientific credibility rather than emphasizing the quality of caring. Staffing assignments reflected the infant's medical acuity, not taking into account the dynamics of each NICU family. Some of the participants described itemizing their practice, giving top priority to getting the tasks done. The value of sitting down with parents and families was put on hold until all the technical tasks were completed. Often there was limited time for quality communication due to the hectic pace on the unit. At times, the participants' perceived that some of the nursing assignments did not allocate enough time to respond to individual family needs, especially for primary care nurses. While acknowledging the required time to facilitate a collaborative relationship between the primary nurse and the family, the participants believed this constraining factor further added to their physical and emotional burden while practicing primary nursing. In all cases cited by the participants, it was evident that their frustration was with the constraints imposed upon authentic practice of family-centred care and competent, credible nursing practice.

Furthermore, unrestricted visitation meant the welcome door was always open for NICU parents and extended families. As a result, this created a busier

work environment and added to the moral distress of the nursing staff not able to provide worthy time with families. Similar emotions have been described by other acute care nurses (Hutchfield, 1999; West et al., 2005).

Equally as frustrating for the study participants was the lack of consistency with respect to following practice related policies. They recognized following consistent policy was fundamental in the effective implementation of family-centred practice and provided grounds for competent nursing practice. Instances where there was lenience with adhering to the rules of the NICU provoked annoyance among staff and families, consequently creating a hostile working environment. Those nurses who worked within the confines of the policy often did so at the expense of their relationship with the parents and other staff. Following consistent guidelines was felt to be integral in the creation of a positive working environment conducive to promote family involvement. The participants maintained that earning trust of families is essential in establishing a working alliance. Personal conflict negated this trust. Similarly, other research examining the relationship of nurses and parents validate this finding (Brown & Ritchie, 1990; MacKean et al., 2005).

On the surface, the theme of inconsistency was connected with feelings of frustration for the study participants. Digging deeper, the inconsistency in adhering to unit policy was connected with the phenomenon of the "good nurse versus bad nurse". Nurses abiding to the practice standards and policy guidelines were labelled the "mean nurses" because they did not allow for exceptions to the rules. Nurses found themselves torn between wanting to be the well-liked or the

"good nurse" verses the "mean nurse" who followed the rules known to benefit the unit in the long-run. For instance, even though a visiting policy is in place in the NICU, controlling the number of visitors was seen as being left up to the discretion of the bedside nurse. The participants equated lenience in applying the visiting policy and allowing more visitors at the bedside with being liked by the families. Limiting the visitors to what is dictated by the policy correlated with being a "mean nurse". For the participants in this study, the "mean nurse versus good nurse" phenomenon further divided the cohesiveness of the working relationships in the NICU.

Positive versus Negative Family Interactions

The link between positive family-centred care experiences and the resulting positive nurse-family interaction facilitated the participants' desire to commit to providing compassionate, respectful, personalized infant/family care; thus, they found satisfaction and pride in practicing authentically. Forming close relationships with the parents was associated with "respect" and "trust". As a result, the study participants spoke of a "sense of accomplishment" and increased job satisfaction in their work environment.

Furthermore, developing a rapport with the NICU parents and families influenced the participants' desire to seek experiences in caring for infants on a continuous and consistent basis. This style of practice was known as primary care nursing. For the study participants, this type of nursing service offered personalized care for the NICU infant and families. In addition, the participants felt that they were directly involved in collaborative care and over time, they saw

the results of their efforts as the NICU infants and families prepared for discharge home. Primary care nursing facilitated a therapeutic partnership between health care staff and families and was associated with providing, by their definition, family-centred care.

Despite the widespread recognition of primary nursing, to date there has been little empirical research analyzing this method of nursing practice. Furthermore, existing literature on primary care varies from its definition to its actualization into practice, further limiting comparisons to previous studies. Although earlier research has linked primary care with increased job satisfaction and less work-related stress (Allen & Vitale-Nolen, 2005; Sellick, et al., 2003; Thokgamo, 2003), each study describes a different organizational system of primary care practice. Regardless, the findings of this research provide evidence relating positive primary care experiences with increased job satisfaction.

Negative family-staff interactions were associated with negative thoughts and reactions from the study participants. These stories were expressed with much emotion during the interviews and for some participants, the experiences were told in great detail. For one participant, the same story was shared during multiple interviews, illustrating how important the experience was for her. Although there were variations in the narratives amongst the study participants, their feelings of frustration and emotional turmoil were a common theme. At times, the interview focused on reliving the negative experience and stories would trigger synergistic narratives. The participants' feeling of being "disrespected" by any NICU family members was thought to hinder a family-focused environment.

When this occurred, the participants acknowledged not wanting to be in direct contact with the family and consequently the family would be labelled "difficult" or "high needs".

These negative experiences created a division of care and ultimately contributed to inauthentic family-centred practice initiatives. The participants would speak about "us", meaning the nurse, versus "them", meaning the family, instead of "we", implying a collective terminology. The collaboration was fragmented. These negative effects not only affect the well-being of the family but also the well-being of the staff and ultimately were reflected in the mood of the workplace environment.

Collaborative Partnerships versus Paternalist Care

Based on the nurses in this study, some participants experienced role ambiguity which contributed to interpersonal conflict. Role conflict was a source of job related strain and consequently limited their ability and willingness to fully practice the family-centred approach. The participants perceived a need to define the "roles" in the NICU: the role of the family and the role of the health care provider. As described by Bruce and Ritchie, this phenomenon is not new.

> Forty years ago, the roles of nurses and parents were clearly defined and parents and nurses had relatively uncomplicated relationships…Today, in general, parents have access to their hospitalized children 24 hours a day and are free to participate in their care. However, the roles of the parent in the hospital and the roles of the nurses in caring for parents of hospitalized children are poorly defined, and their rights and responsibilities in relation to each other are not clear (1990, p. 28).

Although each of the participants recognized the importance of building collaborative relationships between the parents and multidisciplinary team, at

times, the relational component was hindered by the perception that there needed to be "set limitations" in providing family-centred care. Some participants reported feeling ambivalent in facilitating this practice approach when there was a "clash of judgment" between the NICU family and the health care team regarding the infant's management of care. Consequently, a paternalistic attitude where the health care professional was revered as the expert in patient care was prevalent in their stories.

According to the literature on implementing family-centred care in the critical care setting and paediatric population, this finding is consistent with earlier research (Ahmann, 1994; Brown & Ritchie, 1990; Bruce & Ritchie, 1997; Caty et al., 2001; Hegedus, Madden & Neuberg, 1997; Heermann & Wilson, 2000; Lee, 2004; MacKean et al., 2005). As discussed by MacKean et al., "although a collaborative relationship between families and health care providers is a central element in most conceptualizations of family-centered care, [their research findings illustrated] that when family-centered care is operationalzed, the collaborative processes often disappear" (p. 81). Primarily the roles of the family and health care team are defined and driven by the professionals, not mutually determined by the partnership, which is a fundamental element of family-centred care (Brown & Ritchie, 1990; Griffin, 2006; MacKean et al.; Heermann & Wilson, 2000). In this study, the findings indicate that some participants struggle with placing the needs of the families before their own and support the philosophy of "making [medical] decisions based on [the health provider's] knowledge and expertise of what is best for the baby, where parents may be part of the

conversation, but not the decision [maker]". Family-centred care was seen as "involving parents in basic care that parents would normally provide for the infant if [the infant] was not in the NICU".

Similarly, Heermann and Wilson (2000), in studying nurses' experiences working with NICU families, found family-centred practice experiences were associated with nurses' feeling intimidated and looking for control. Fostering collaborative partnerships was challenged as nurses felt they were giving up something very central to their professional identity and their technical expertise (Heermann & Wilson).

Furthermore, some of the participants described a hierarchical pattern in the NICU and spoke of the social norms in respect for the "office" of the doctor. The nature of the acute care setting has encouraged this arrangement since its inception (Copnell et al., 2004). For these nurses, this hierarchy was seen as devaluing what nurses bring to the bedside in caring for NICU infants and families. This was especially frustrating when the participants acknowledged family-centred care was practiced more by the bedside nurses, under the direction of "superiors". Other disciplines, although claiming to be incorporating the philosophy into care, were seen as not having to practice the tenets fully because these care providers were not in "direct contact with the babies and families except for a few minutes here and there". The physicians and nurse managers, although leaders by position, were identified as not actively participating in family-centred care therefore not having the practical wisdom of the bedside nurse to provide direction on how to facilitate this practice approach.

In summary, the findings highlight the neonatal nurses' struggle internally and externally with trying to incorporate the multiple facets of family-centred care into their daily nursing practice. For each participant, the authentic practice of family-centred care focused on their positive and negative work experiences of collaborating with families. In addition, their practice experiences were subject to the confines of the mood of the workplace environment.

Turning back to my original research questions – What are nurses' perceptions and reported practices in implementing family-centred care in the NICU setting? What advice might nurses provide for facilitating a more consistent family-centred care approach into practice? – I find myself thinking about how the participants' focused primarily on the constraints under which they genuinely tried to practice family-centred care in the current NICU environment. These experiences needed to be explored for their true meaning in order to be able to concentrate on how we might improve practice. I now concentrate on what these nurses taught me and put forth recommendations to enhance a family-centred approach to nursing practice.

Implications and Recommendations for Nursing Practice

The purpose of this study was to explore nurses' experiences in practicing family-centred care in the NICU environment, and furthermore, to gain a better understanding of what would be useful to assist these nurses in facilitating this approach to practice. As a part of their process of reflecting and finding meaning in their practice experiences, the participants were stimulated to put forward recommendations to aid in facilitating a family-centred approach to care. In the

following paragraphs the participant narratives are interpreted in relation to their suggestions in enhancing family-centred care practice. Strategies to enhance participation in this approach were identified with respect to the functional reality of everyday practice experiences. In addition, I add my own recommendations which will be italicized in a bold type format.

Amongst the findings of this research study are implications for nursing in the areas of providing education, fostering a positive workplace culture and addressing unit policy. The participants' family-centred nursing practice was thought to be influenced by these factors.

Education

One difficulty facing nurses and other health care providers in the NICU setting is the struggle with how to create collaborative partnerships with the parents and families. In the attempt to provide family-centred care, the creation of supportive environments requires an understanding about the roles of the professionals and the families in the NICU setting. Although the health care professionals are encouraged to create a family-focused environment, the attitudes and understanding on how to facilitate these relationships is limited. Furthermore, "many clinicians remain uncertain about exactly what family-centred care really means" (Rosenbaum et al., 1998, p.1).

Professional Family-Centred Care Education

The study participants voiced their concerns about the lack of understanding in providing quality family-centred care in the NICU. As stated by Bruce and Ritchie "to effectively practice family-centred care, nurses must be

clear and consistent in their understanding and beliefs about the care of children and their families" (1997, p.214). The participants perceived uncertainty not only among the nursing staff but also among the various health care professionals providing care in the NICU. One participant stated "we need to understand the information". The lack of knowledge and skills to fully practice this approach was identified and visualizing the reality of Canadian practice was questioned.

> I would like to see more education, um, let the people read the articles and see how well it does. Show us examples…where family-centred care is working and where it is effective…

According to the participants, family-centred care practice was felt to have changed dramatically over the past decade; however the European culture was believed to be more functionally progressive with respect to the promotion and facilitation of this approach. The North American culture was perceived to be different. Hence, the participants' practice reflections of what full parental participation meant was interpreted as being less imperative in providing the concept of family-centred care to practice. As one participant stated "do you think mom 'X' would have three babies stuck on her 24-hours a day with four other children at home [in Canada]? The reality is that she is stressed with the other four children at home [and] she's [not] getting any support". It was seen as usual that "mothers were not with the babies all the time…and that our society was [just] different".

Inter-professional education reflecting the importance of encouraging and supporting parental and family presence and participation requires further development and the participants recognized this. With the expansion of bed

numbers over the past year, there has been tremendous strain placed on the experienced nurses at the RAH. Orienting and mentoring of new staff, coupled with an over census limit of critically ill infants admitted into the unit have left the staff struggling with "getting the job done". The participants acknowledge that taking the time to further education and professional development is another task on an already full slate. However, it is imperative to fully understand the family-centred framework in order to be able to practice with full insight.

Until recently, in the RAH NICU, extra educational opportunities were limited to applying for yearly conference funding. In the past year, unit-held, monthly learning sessions have been available for staff on topics related to neonatal care. Lately the focus of the teaching sessions has been on developmental care and its imperatives.

In keeping with implementing the NIDCAP model of care in the NICU at the RAH, additional training is needed for all NICU staff, about NIDCAP practice initiatives. In recognition of the participating nurses' vulnerability, providing proper education for the staff in turn would give the nurses the opportunity to gain the knowledge to practice. This would acknowledge how integral nurses are for NIDCAP implementation and it would value what they do well.

The participants acknowledged that the care provided in the NICU influences patient outcome. The importance of long-term infant development and the responsibility of the health care staff in understanding the goals of providing

specialized care to the infants in the NICU were basic in guiding family-centred care.

> It should be just something that's like 'this is what we do; we are family- centred care' and what…that means ... Every person knows… what that means, and that this is what our unit does and supports. It's a mentality.
>
> … We have thousand of babies going out that are very, very ill and we didn't have that before and now these children are 10 years old and we know how these children are turning out and we need to change our practice in order to make these children into children that can lead happy, normal lives… we need to understand the [family-centred care] information.

Communication Tools

The study participants felt that the provision of education and additional resources to help them examine some of the emotionally demanding experiences encountered in the NICU would contribute to enhancing cohesive family-centred practice. It was recognized that the current NICU environment was at times extremely stressful. Interpersonal skills and "tools" to assist the nurses in coping with difficult situations were perceived to alleviate the participants' feelings of frustration and powerlessness that contributed to negativity associated with family-centred care practice.

> There [are] more educated people, there are more *high stressed* people, the parents are getting older that are having babies, they're more needy, have more questions than they use to…
>
> I guess what we have to do is…if we can't intervene at the family level [in providing support] then we'll have to intervene at the bedside nurse level. Give us tools to deal with the difficult parents…which [is what] we need to learn. We need the education.

In such circumstances, one participant spoke of providing a staff psychologist for the nursing staff, thinking a psychologist may help "identify what

the areas of concern are on this unit" and provide the nurses "the tools to deal with some of the problems" encountered with working in an intensive care environment. The other participants were less willing to speak to an outside individual and as one participant said "I don't think I need psychological help to deal with what is happening right now, things need to change here. *Period*". Further to the discussion was the comment "I think we should change the situation so people don't need counselling to come to work".

The unwillingness to speak to an outsider about the "concerns on the unit" stems from previous experiences where participants talking about the problems did not produce solutions. However, an important component of the above suggestion is providing "tools" for dealing with difficult situations. Providing tools to guide the health care team in caring for diverse families and family needs is imperative in fostering partnerships that support both parties.

Additional education and resources are needed to help staff deal with the emotionally demanding experiences encountered in the NICU. Specifically, there needs to be accessible teaching sessions giving practical advice and coping strategies on how to negotiate or diffuse stressful workplace conflict. To support the philosophy of family-centred care, attention must be paid to teaching and supporting nurses' communication skills and relationship building with self, peers, and families" (Griffin, 2006, p.100). Harrison writes "communication in the NICU is a source of frustration to parents and caregivers alike" (1993, p.644). Courses in communication should be an important part of nursing education.

Providing Supportive Workplace Culture

Although the participants identified the need for educational support and resources, they also recognized the need for respectful information sharing. They cited instances where family-centred care and developmentally supportive care initiatives were perceived as condescending, disrespectful and critical to the study participants.

> I think the, the information is so important…and it's not being sent out in a respectful way…the education part of it is not coming out in the right way, but the information that's coming out is so important, like I can't even stress how important it is but I know it's not coming out in the right way.

> [Everybody] needs to understand that this is how people are feeling and we need to get the information out but how to do that, I don't know. We need…to educate every single person that works here.

> If they want people to get on board then they better watch the tactics that they use to release their information or their views on things.

In an intense and stressful environment such as the NICU, staff support is essential in providing a positive workplace culture, mitigating unnecessary negative practice experiences. According to the study participants, the workplace atmosphere directly impacted how they experienced environmental stress, their feelings of powerlessness and their ability to cope while caring for critically ill infants and their families. Negative practice experiences coupled with a perceived lack of supportive workplace culture influenced the participants' commitment in providing family-centred care in the NICU.

Multidisciplinary support

The study participants spoke of their desire for increased support by all members of the health care team, including the nursing unit managers and their

co-workers. The lack of support presented a significant barrier to practicing family-centred care and discussion about how to promote positive interactions among the staff was extensive. As one participant explained, prior to recommending constructive solutions, their "venting" about certain experiences helped relieve their negativity but she recognized that destructive criticism did not foster culture change.

> We vent to each other enough…It's got to be constructive. What we're doing has to be constructive and it has to be able to make a change for the better because *bitching* and *venting* does help, it does diffuse how you feel. You feel better after you do it but it doesn't *change* anything.

However, the participants needed to deal with their practice frustration in order to be forthcoming with possible solutions to the perceived practice barrier. The lack of support and respect in the workplace threatened their self-esteem and motivation to provide unconditional supportive care for infants and families.

> And I think the ones that, the people caring for our own [nurses] are our own [nurses]. The ones supporting us are the bedside nurses…But that's each other, in an informal way…But that's the problem…It has to go beyond that because if we're not respected and supported [by the health care team] then how are the parents going to respect and support us.

> …something needs to *change* to support the people who are doing the looking after…

The study participants' tolerance to perceived "staff abuse" by parents was zero. When the participants felt a lack of mutual trust or disrespect, they immediately ceased authentic family-centred practice subsequently diminishing job satisfaction. Although these experienced practitioners recognized that having an infant admitted in the NICU was a stressful time for parents and families, the

participants refused to endure disrespectful comments and behaviour of the NICU families. In speaking to management, they felt their concerns were often disregarded. Furthermore, there would be no reprimand for the inappropriate comments or behaviour. The participants felt that if they could voice their concerns and receive unconditional support from the health care team they would experience less moral distress. As suggested by some of the participants, having a manager or physician speak to the family first hand in times of staff disrespect, illustrated support for the staff and ultimately their value in the team setting. The study participants felt that they had no authority in diffusing conflict among families and staff, a reflection of the workplace culture.

> …the first incident with that mother where there was an issue, she should have been *talked to*. That's how you support your bedside nurses by not letting [families] *manipulate* the staff or if you find that your bedside nurses are upset then as a charge person you need to come in and deal with it right away…

> The [unit managers or physicians] sit down with somebody [a parent or family member]…and…say 'I understand that you are going through a lot of stress right now and we're here and this is our job and we see families like you all the time and this is our job to work with families like you, but you are going to be here for a long time. You have to have some *trust* in the people that are looking after *your* child'.

Management and other health care professionals must work toward promoting a respectful team building environment supporting empowerment among staff nurses. In providing a supportive workplace culture, it is imperative that we expose the importance of nurses as members of the health care team. It is unfortunate that the participants felt a need to reflect on their "low role on the totem pole" status in the NICU. It is time that nurses make explicit the essential qualities their profession practices. By virtue of their continuous presence in the

high-stress environment of the NICU, nurses must be assertive, confident and well respected by all members of the team, including the families. Nursing management behaviours and leadership style significantly impacts the professional development and clinical practice of staff nurses (VanOyen- Force, 2005). If nurses feel that their presence in the unit is not valued and respected how can we expect nurses to value and respect the presence of the families in the NICU? This is an important consideration in an organization that currently advocates family-centred care but happens to tolerate and implicitly support a hierarchical presence and structure.

Staff survey. With the networking that takes place in the NICU during "coffee talk", one of the study participants overheard a discussion among staff about conducting an informal "staff satisfaction" survey. The purpose of the survey was to assist in identifying "areas of concern on the unit" for the nursing staff and in turn would offer suggestions and direction for improving the workplace culture. The staff survey was in response to "staff feeling that they weren't being heard". The survey was not pursued by the nursing staff because of past experiences where nurses making suggestions were told "be more professional" and "do your job".

Nurses must take ownership of their own values and actively address practice initiatives based on those beliefs such as establishing working partnerships with other health care professionals and families. Instead of rendering themselves incapacitated to transform the barriers in which they practice, nurses have choices and they must act upon those in order to be "true" to

themselves or authentic professional practitioners. Instead of using their anger in a passive, destructive way, these nurses must constructively problem-solve in the pursuit of promoting their value and their values amongst the health care team.

An informal survey identifying "sources of workplace stress, their preferred methods for dealing with stress, and suggestions for employer-based assistance" has been recommended and successfully implemented in other intensive care centers (Ewing & Carter, 2004, p.47). Vanderbilt NICU, Nashville, Tennessee, responded to struggling with recruitment and retention of nursing staff, by providing a survey for all NICU staff members addressing major stressors in the workplace (Ewing & Carter). In response to the survey, an ongoing support program entitled "Partners in Caring" was developed (Ewing & Carter).

Policy Guidelines

Primary care

In addressing the conceptual framework of primary care and recognizing the participants' perception of practicing primary care in the clinical setting, the recommendations put forth by the study participants encompassed practice initiatives and policy guidelines. Not only did the participants explore their perceptions of practice in the clinical setting, they discussed how the process of arranging primary care teams was biased. Acknowledging that recently an informal primary care committee has been developed for the unit, the participants hoped that practice guidelines would be addressed during these meetings. However, the participants' perception that there was unbalanced staff-manager

representation on the committee which limited their optimism for facilitating changes in practice.

In the effort to put forth practice directives, a formal committee needs to be developed with adequate representation of the various health care professionals working in the NICU. Formal guidelines must encompass medical, nursing and managerial practice initiatives as well as standardize policy on infant selection for primary care and family participation.

Peer mentoring

Thought to add to an already strained NICU environment was the division between the "junior nurses" and the "veteran nurses". Less experienced staff were felt to not have the "maturity to deal' with all facets of NICU care versus the "experienced staff" who had practice "expertise". The newer nurses were in a perpetual learning state and "basically [were] learning how to deal with the technical parts" of NICU care whereas the experienced nurses were expected to be incorporating a family-centred approach in the context of completing all their acute care interventions. The participants understood the need to develop technology-related knowledge and practice experience during the first two years of NICU nursing. Learning to "build a rapport" with families came with their practice experience.

In their vision of what was important in enhancing the professional growth of the novice nurse, the study participants discussed that primary care teams should be limited to the more experienced staff. Having novice nurses on primary care teams was identified as not in the best interest of either the infant or the

inexperienced nurse. Although this was their perception, the participants did not know how to act upon or address this vision.

Peer mentorship addresses the challenge of nursing staff cohesiveness through establishment of dyadic relationships developed over a lengthy period of time between experienced–junior nurses; experienced– experienced nurses.

> Mentoring offers a means for young nurses to successfully navigate the developmental task of moving from being a novice to becoming an expert. For the maturing nurse, mentoring offers the chance to pass on to others the knowledge gained through experience. Mentoring opens up the possibility of growth and supports gaining new skills essential for the changing practice of nursing (Scott, 2005, p.52).

This method of nursing practice has been associated with generating a positive and nurturing environment for both involved (Glass & Walter, 2000; Scott, 2005). The mentor becomes a role model, sharing their knowledge and experiences with a "protégé". As the process unfolds, a strong relationship is established and overtime each member becomes committed to the personal and professional growth of each other resulting in shared caring and mutual support (Glass & Walter).

In summary, the study participants' recommendations in improving family-centred care focused on minimizing their perceived practice barriers. Collectively, their suggestions and the study recommendations provide direction to further enhance family- centred care and authentic neonatal nursing care.

Strengths and Limitations

The strength of the study lies in the method utilized to conduct the study and analyze the narrative data (Brink & Wood, 2001). The aim of this study was to explore a group of neonatal nurses' family-centred practices and uncover what

those experiences meant from their perspective. In light of my research questions, purpose, and previous NICU "history", interpretive phenomenology was the best approach to utilize.

Phenomenology as a research method has been subject to critics largely because of the very reasons I chose this methodology (Koch, 1995; Koch, 2006; Benner, 1994). The philosophical underpinnings of interpretive phenomenology encompass examining human experience as it happens, in the context of what we know to be true based on past personal experience (Koch, 1995; Moran 2002). The experiences and understandings of both the researcher and the participant are thus integrated to produce the conclusive meanings found in interpretive research. To critics of phenomenology stating "researcher bias interferes with clean results" (Lynch-Sauer, 1985, p.106), I would argue that my personal knowledge and neonatal nursing experience strengthened the study by producing research that was logical in meaning. This also provided theoretical sensitivity when interviewing and analyzing data.

The participants were selected for this study using the purposive sampling method; therefore nurses were selected based on their ability to provide comprehensive family-centered care practice experiences. The sample size was limited to five participants with the intention to provide meaningful results. By limiting the sample, I was able to conduct multiple interviews with the same participants. The second group interview provided an opportunity to clarify and verify data, strengthening the study design.

The study participants were diverse in their years of practice experience, ranging from five to 28 years. Each nurse provided a variation in their narrative contributions in the interview setting. However, some participants were more vocal and consequently were heard more often.

Conducting small group interviews allowed for a more naturalistic way to study the practical knowledge and events of the participants (Benner, 1994). Although this atmosphere created an informal "coffee break" setting, at times the participants would interrupt one another and not allow for full explication of events and experiences. Other times, synergistic stories provoked further reflection and discussion. The small group interviews did not allow for confidentiality among participants. Thus, it must be recognized that certain experiences may not have been divulged in this type of interview setting due to the personal nature of what was being discussed.

To strengthen the study design, multiple interviews were conducted. The second small group interview provided an opportunity to clarify and verify data. I was able to verify the accuracy of what the participants said and review my thematic interpretation of the narrative data. The timing between the first and second interview sessions was nine weeks. This afforded me time to have the interviews transcribed, as well as enough time to verify accuracy of the transcribed data and data interpretation. However, for the participants, this time lapse challenged their memory recall of experiences discussed in the initial interviews but perhaps strengthened the consistency value in resonating with the participants of their recall of the originally expressed thoughts. For some

participants, evaluating and reviewing the thematic interpretation encouraged reflection of the same stories discussed in the previous interview. As the participants validated the interpretation, the study's credibility was supported.

A second reader completed a blind reading and interpretation of all transcribed, narrative data. Dr. Sherrill Conroy was my second reader and following her interpretive work, an audit of my interpretation worksheet was completed. "This process ensured the quality of the interpretation and provided verification that the research [was] performed in accordance with [the] stated intensions" (Conroy, 2003, p.30). This reinforced the trustworthiness of the research.

Although the findings may not be applicable to all NICU environments or other intensive care nurses, it was not my intent to generalize the findings to other clinical situations. In interpretive phenomenology, "the interpretive accounts will not be true for all persons at all times because concerns and issues will be different depending on the situation and possibilities of the person" (Benner, 1994, p.79). My priority is to accurately reflect the experiences of neonatal nurses in the hopes that the research findings are meaningful and applicable in terms of their own nursing practice. The applicability of this research was confirmed by the nurses participating in the study. As one participant stated at the end of the final group session, "I hope you can do something with this. It could really help".

In keeping with the philosophical underpinnings of interpretive phenomenology, the narrative context must be evaluated by considering the

entirety of the experience. Any given situation is "shaped by the person's background history, culture, society and language" (Benner, 1994, p.79). This brings to light an important consideration. In reflecting on the participants' stories, the context of what was occurring on the unit at the time of the interviews dynamically contributed to the findings of the research. As previously mentioned, there was high patient acuity, extensive orientation of new nursing staff as well as unit issues warranting "emergent unit meetings" between management, the local nursing union and staff. Some of the participants' comments like "morale is in the toilet" or the unit is like "one big boil that is festering" revealed the negative emotional state these nurses were experiencing. It would be interesting to speak to these participants again during a time when the acuity on the unit is less intense, in turn placing fewer physical demands on the nursing staff. A subsequent study of participants' practical experiences may yield different results.

Implications for Future Research

This interpretive study was conducted to gain insight into the nursing practice of family-centred care in the NICU. The exploratory nature of the study design raised further questions and provoked thinking in areas requiring further investigation. Future nursing research could address these interests.

Some of the study findings had implications for further examination past that of only the nurse' experiences of family-centred care. A comparative study examining families', managers' as well as the nurses' (both novice and experienced) perspectives on family-centred care would yield meaningful insight into the experiences of the respective groups. Specifically, exploring the

dimension of family-centred practice and the interrelationship in establishing collaborative relationships between families and direct care providers would allow examination of the current policy and practice from a joint perspective. Furthermore, these findings would provide the nurses the realization of how their practice is perceived by NICU families.

It would also be interesting to study workplace culture with respect to the examining authentic, inauthentic and undifferentiated family-centred care practice. Although the findings of this study identified the need for a supportive workplace culture, exploring the unit culture in relation to management initiatives and nursing practice was not fully uncovered or disclosed.

Another area on which future research might concentrate is the actualization of primary care into neonatal nursing practice. Exploring the process of implementing and maintaining a primary nursing system would provide measures to support family-centred practice initiatives.

After completing the interviews and the thematic analysis, I found myself wondering what direction the interviews would have taken with a different group comprised of both novice and veteran practitioners. It was my preconception that in order to discuss family-centred experiences, my sample needed to consist of well established, experienced nurses with plenty of "experience" to draw upon. By limiting my sample selection criterion, I may have limited the potential for more meaningful results.

Concluding Remarks

In this chapter, the research findings have been reviewed within an interpretive context. The recommendations derived from the findings and implications for nursing practice were discussed. In addition, the strengths and limitations of the study were identified and future research arising from this foundational work was presented.

In summary, using an interpretive phenomenological method of inquiry, I explored nurses' experiences and their perceptions of family-centred care practice while caring for neonates and their families in the NICU setting. Although the results only reflect the lived experiences of the sample population, the goal of this study was to identify the experience of veteran neonatal nurses as they practice the family-centred concept of care. Through this critical reflection, I was reacquainted with the intricacy of nursing practice I had forgotten and taken for granted over the years. In reflecting on the spoken words of one study participant "it's tough getting that involved with people during these fragile times in their lives", exploring the experiences of neonatal nurses provided the foundation in understanding family centred-care practice in the confines of the NICU. This is essential in providing direction to enhance effective family-centred practice initiatives. With the help of the research participants, an improved understanding of their ability to practice the family-centred care tenets was gained.

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APPENDIX A

Letter of Invitation for Nurses

Project Title: Nurses' Perceptions of Family-Centred Care Practice in the Neonatal Intensive Care Unit

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I would like to invite you to participate in a research study exploring nurses' perceptions of practicing family-centred care within the Neonatal Intensive Care Unit (NICU). The purpose of this study is to uncover the everyday experiences of neonatal nurses' family-centred care practices. This research is important because knowledge gathered from this study will enhance family-centred neonatal nursing care.

I am a Neonatal Nurse Practitioner Intern, who is currently finishing her Master of Nursing. If you are interested in participating in this study or would like more information about the study, please call either myself, the investigator or Dr. Sherrill Conroy. Thank you very much for your consideration of participating and assisting in this study.

Yours Sincerely,

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APPENDIX B

Letter of Explanation for Nurses

Project Title: Nurses' Perceptions of Family-Centred Care Practice in the Neonatal Intensive Care Unit

Investigator: Tara Follett, BScN, MN(c)
Graduate Student, Faculty of Nursing, University of Alberta
Supervisor: Dr. Sherrill Conroy, RN, BN, MEd, DPHIL
Assistant Professor, Faculty of Nursing, University of Alberta
Office Phone Number (780) 492-9043
Sherrill.conroy@ualberta.ca

Purpose: I am a Neonatal Nurse Practitioner Intern and a master student in the Faculty of Nursing at the University of Alberta. Drawing from my background in neonatal nursing, I am interested in exploring nurses' perceptions of practicing family-centred care within the Neonatal Intensive Care Unit (NICU). The purpose of this study is to uncover the everyday experiences of neonatal nurses' family-centred care practices. I am doing this study to fulfill requirements for a Master in Nursing degree through the University of Alberta.

Procedure: I would like to invite you to participate in my research study as a Registered Nurse working in the Neonatal Intensive Care Unit (NICU). I am asking you to participate in two small group interviews with myself and up to four other participants, who are also Registered Nurses. Each small group interview will be about 60-90 minutes in length. Permission will be requested to audio-tape the interview to provide an accurate record of our conversation. You may request the tape recorder be turned off at anytime during the interview. Notes will also be taken. After the initial interview, I will transcribe the conversation into written text and look to understand your perceptions of practicing family-centred care within the NICU. I will share the written interpretation of these conversations with all the participants during the second interview. At that time, I will be asking you to provide feedback and interpretation.

The group interviews will be held in one of the conference rooms at the Royal Alexandra Hospital. You will not be paid for participating in the interviews and there will be no cost to you for participating, except for your time. If you incur any parking costs while participating in the study, I will reimburse you for these expenses. I will require a written receipt and a reimbursement will be paid to you in cash.

Possible benefits: There is no direct benefit to participating in this study. It will provide you with an opportunity to share stories about your experiences with family-centred neonatal nursing practice.

Possible risks: There are no known risks to participating in this study.

Voluntary Participation: Your participation in the interviews is voluntary. You may decline to answer any of the questions. You also have the right to ask questions and ask for more information whenever you like. Even if you have signed the consent, you have the right to remove yourself from the study at anytime. Your position within your workplace will not change if you do not participate in my study.

Confidentiality: Anonymity and privacy will be assured as much as possible however, within group interviews confidentiality cannot be guaranteed due to the nature of group participation. Confidentiality of information shared within the group will be emphasized

to participants at the beginning of each interview. If there is something you would not like discussed or known, please do not feel any pressure to share it with the group. Outside of these interviews the information you provide is strictly private. Code numbers will be used on transcripts and notes. The list of participants along with the code number will be stored separately from the data. The person transcribing the interview audio recordings will sign a confidentiality agreement. Only the investigator and the supervisor will review the tapes, transcriptions and notes. The information and findings of this study may be published or presented at conferences but your name or any material that may identify you will not be used. All data collected will be stored in a locked cupboard in a locked office for at least five years after the study is completed and then destroyed in a confidential manner. Your name will not appear in the study findings. All information will be held strictly confidential, except when professional codes of ethics or the law requires reporting. Once my study is complete you may have a copy of the findings if you want them.

Contact Names: If at any time you have general inquiries about this study, you may contact me or Dr. Sherrill Conroy, the supervisor. The study design has been approved by the Health Research Ethics Board at the University of Alberta. For questions or concerns regarding participant rights and ethical conduct of research, please contact either the Director of Research at the Faculty of Nursing, University of Alberta, Dr. Kovacs Burns at (780)492-3769 or the chair of the Health Research Ethics Board at (780) 492-0302. Both of these individuals have no affiliation with the study project.

Thank you for considering participating in my study. I appreciate your time and willingness to help me explore the everyday experiences of neonatal nurses' family centered care practices within the Neonatal Intensive Care Unit.

Tara Follett, BScN, MN(c)
Master of Nursing Graduate Student
Faculty of Nursing
University of Alberta
Edmonton, Alberta
Office Phone Number (780) 735-5959
Pager number (780) 445-3686

APPENDIX C

Consent Form

Project Title: Nurses' Perceptions of Family-Centred Care Practice in the Neonatal Intensive Care Unit

Investigator:
Tara Follett, BScN, MN(c)
Master of Nursing Graduate Student
Faculty of Nursing, University of Alberta
Office Phone Number (780) 735-5959

Supervisor:
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Professor, Faculty of Nursing
University of Alberta
Office Phone Number (780) 492-9043

Consent of Nurse Participant

Do you understand that you have been asked to be in a research study?	**Yes**	**No**
Have you read and received a copy of the attached information sheet?	**Yes**	**No**
Do you understand the benefits and risks involved in taking part this research study?	**Yes**	**No**
Have you had the opportunity to ask questions and discuss the study?	**Yes**	**No**
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your position as an employee.	**Yes**	**No**
Has the issue of confidentiality been explained to you?	**Yes**	**No**
Do you understand that the findings may be published or presented at conferences but your name or any material that may identify you will not be used?	**Yes**	**No**
Do you understand who will have access to your study records?	**Yes**	**No**

Would you like a report of the research findings? If so, Address:

_____

This consent was explained to me by: _____ Date: _____

I agree to take part in this study

_____ _____

Signature of Research Participant | Printed Name

_____ _____

Signature of Witness (if available) | Date

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate

_____ _____

Signature of Investigator | Printed Name

APPENDIX D

Demographic Questionnaire

Project Title: Nurses' Perceptions of Family-Centred Care Practice in the Neonatal Intensive Care Unit

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Supervisor:
Dr. Sherrill Conroy, RN, BN, Med, DPHIL
Professor, Faculty of Nursing
University of Alberta
Office Phone Number (780) 492-9043

Please complete the following general information

Age in years: 20-30 _____

31-40 _____

41-50 _____

51-60 _____

Years of experience in the Neonatal Intensive Care Unit: _____

Highest level of education: University Degree _____

Post Secondary _____

Other _____

APPENDIX E
Health Research Ethics Approval Form

HEALTH RESEARCH ETHICS APPROVAL FORM

Date: February 2006

Name of Applicant: **Dr. Sherrill Conroy**

Organization: **University of Alberta**

Department:

Project Title: **Nurses' perceptions of practicing family-centred care in the neonatal intensive care unit (NICU)**

The Health Research Ethics Board (HREB) has reviewed the protocol for this project and found it to be acceptable within the limitations of human experimentation. The HREB has also reviewed and approved the subject information letter and consent form

The approval for the study as presented is valid for one year. It may be extended following completion of the yearly report form. Any proposed changes to the study must be submitted to the Health Research Ethics Board for approval. Written notification must be sent to the HREB when the project is complete or terminated.

Special Comments:

FEB 2 3 2006

Dr. Glenn Griener, PhD
Chair of the Health Research Ethics Board
(B: Health Research)

Date of Approval Release

File Number: B-120206